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ABSTRACT

The book examines approaches for developing supports for families with special needs. Following a brief introduction to the needs of families with disabled family members, a section considers basic questions to be used in determining the needs of individuals within the family and of the family as a whole. An example of short-term care services is offered. Next, steps in deciding the types of family support to obtain are considered. Three types of respite care (in the family's own home, in a respite worker's home, and in a center) are explored and examples of each are given along with sample forms and a discussion of provider qualities and training. Additional aspects of respite care addressed are financial considerations, possibilities for respite through other programs (such as homemaker services and home health aide programs), and public awareness. (CL)

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KEEPING FAMILIES TOGETHER

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PROVIDING RESPITE AND OTHER SHORT-TERM CARE FOR PEOPLE WITH DISABILITIES

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Cover illustration: Jane White, Kenai, AK, with son Matt, one of the Whites' three children. The family uses a respite program for short-term care for daughter Jenny who is disabled.

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Many thanks to the individuals and families
around the state who gave of their time
and experience to make this book possible.

Sharon Mattingly and (from left) children Whitney, Regan and Bart, Fairbanks, AK. The Mattinglys use in-home and center-based respite care.

FAMILY SUPPORT:
WAYS OF HELPING FAMILIES STAY TOGETHER

If you stop and think about it, families - just like individuals - go through a lot of changes. Circumstances change, needs change, and it becomes necessary for families to look to relatives, friends, and the larger community for different things at different times.

For example:

When a family adds a child for the first time, the parents look to parts of the community they may have overlooked before - to the school, to different kinds of health care and medical services. They may also look to other people in new ways. They may look to relatives or friends for help and support in learning how to care for their child. Family and friends can fill in when it's important for the parents to have time away for medical appointments, shopping, other errands, or family business - or simply to have a break from the child care responsibilities. And the parents can return the favor - they can take care of their brother's kids or the kids next door when those families need a hand. Simply, it is the natural system of families helping families, friends helping friends. It's a system that has been around - and has worked - for a long time.

It doesn't, however, work all the time. A lot of people move around a good deal, away from their home communities and larger families. Even in instances where relatives or friends are nearby, they're often busy with their own jobs and responsibilities. It has become necessary for families to look elsewhere when they need that helping hand. They look to day care centers, babysitters and other means of child care to give them the time they need for other responsibilities. And while those kinds of care have not been around as long as the extended family, they have become a very natural part of the family system for many people.

But those services - at least as we usually think of them - don't work all the time either. In families where a child or adult is severely disabled or for other reasons requires a substantial amount of

". . .In a lot of cases you can't just call up the fifteen or sixteen-year-old babysitter from next door to come and care for your handicapped child. . . There's a lot more to it than that."

care, it can be hard to find the kind of help that's needed. A family member who's disabled can have physical or medical needs, for example, which require certain skills. When parents or other family members need a break to take care of other responsibilities - or just a break, period - it may be impossible to find someone qualified to fill in, even for a few hours. And yet the family needs the help, the time to look after things, just as much as any family. Maybe more so. In fact, many families with a severely disabled child, for example, can find it difficult to stay together as a family if they don't get the needed support. There can be very hard times all the way around:

Parents don't have the time they need for the family and each other. The other children in the family may not get the attention they need. The person who needs the care - child or adult - doesn't get the chance for independence outside the family. Sometimes all of these difficulties just become part of the family's day-to-day life, taking a big toll on everybody. Other times, when the difficulties get to be too great, families can seriously question whether the disabled person should continue living at home. Sometimes an institution may seem like the only answer - and that usually means placing the person somewhere away from the family's home community.

More often, the pressure just keeps building and shows itself in

anger, frustration, impatience - all of which can result in rejection, mental or physical abuse of a family member, divorce and other serious problems.

This book is about some different answers for families. It's about turning those negative pressures into positive actions, about finding the help necessary to keep families together and working well as families. It's about ways of providing care for people who are disabled - ways that are natural to families, that take after the accepted kinds of child care and family care that people have worked out for themselves over the years.

Most importantly, this is a book about developing supports for families with special needs that are not so different from family supports in general. It is concerned, first and foremost, that services not set families with special needs apart from the rest of the community, that they don't isolate family members who are disabled. It is, finally, not just a book about starting new services for families, but one which encourages families whenever possible to fit themselves into existing programs serving the larger community. That means taking a good look around for services flexible enough (to be bent) to meet special needs.

We have included in the book examples of a variety of family supports, as well as advice and guidelines from people in the state who have developed them and are using them. We hope this information can be helpful to your family and to others in your community.

Sue Behnert, Juneau, AK, and son Carl. Access to medical care has been an important part of the respite program for them.

A GOOD QUESTION: WHERE TO START?

1. DECIDING WHAT YOUR NEEDS ARE

When people look beyond relatives and friends and begin to think about other ways of providing short-term care for family members who are disabled, it's important to keep in mind that care can be provided in a number of different ways. Some of those ways may already be available in your community; others may need to be established. However, before you can decide what kind of care is going to meet your needs (and those of other families in the community), you'll have to have a good idea of what those needs are, including:

Your needs as a parent, guardian, spouse or other responsible party;
the needs of the family member who requires the care; and,
the needs of other members of the family (like spouse or siblings).

To decide just what those needs are, it should be helpful to ask yourself - and others in your family - some basic questions. The answers can then serve as a guide for your efforts to find the kind(s) of short-term care that are right for you. Here are some questions you might start with:

How often? For what purposes?

As a parent, guardian or other family member, how often will you want or need short-term care for someone in your family? For what purposes? Will you need it only once in awhile, for special occasions or emergencies, or will you need it on a more regular basis - maybe to spend time with other members of the family, or even to take a job or enroll in school?

Where? What about transportation?

Would you and the person requiring care be more comfortable with care provided in your own home or at another

location (such as someone else's home or a day care center with trained staff, for example)? What are the pros and cons of both options for your family? What about transportation? Are you able to lift (if necessary) and transport the family member who needs care? Would you be able and willing to get that person to another location for care, or would other arrangements have to be made?

"Sometimes (now) I use a regular sitter, but what am I going to do when Heidi's fourteen? Am I going to be able to get a teen-age babysitter to come over and watch her?"

Parent of a handicapped child

Special care requirements?

What are the special requirements of the family member who needs the short-term care? Does he or she have medical problems which make it necessary for the person providing care to have special skills? Or would it be enough for that person to be a responsible individual with the maturity to handle an emergency should one arise?

Again, these kinds of questions can help fill in the details of the kind of care you want. As a further guide, here are three examples of the ways families use short-term care:

A parent is very interested in going back to work on a part-time basis, but is concerned about care for her two-year-old child who is severely disabled. The parent would like her child to participate in an educational day care program, preferably one which includes both children who are and are not disabled. While there is a day care center in the community, the parent doesn't think it serves children who are disabled. To find out more about it, she stopped by to talk with the director. As it turned out, she is not alone in wanting to

locate care for her child; a couple of other parents have expressed the same desire to the center staff. Consequently, the director is willing to work with the families to develop a program which can meet the needs of their children, including the possibility of a part-time staff person who has early childhood and special education training.

For their part, the parents of the disabled youngsters have decided to testify before the local government budget committee on the importance of integrating children with disabilities into regular day care programs. (While family fees are the primary source of support for this day care center, government funds do provide some additional support.) Although nothing has been guaranteed, the ball has started to roll toward the kind of care these families want and need.

Let's look at another example of a parent of a disabled child. This child is severely mentally retarded, and in addition, has serious 'acting-out' behaviors, including violent tantrums. Since his behavior is unpredictable, the child requires almost constant supervision to make certain he doesn't harm himself or others. Although the child goes to school during the day, the attention he requires when he comes home means that the parent has little or no time available to participate in the after-school activities of the other children in the family. Consequently, the parent would like to have short-term care for the disabled child after school - anywhere from one to three afternoons a week from 3 p.m. to 5 p.m. Since the family prefers that the child come to his own home environment after school, they have arranged for a person to care for him in their home. This gives the parent a chance for a break and for some uninterrupted time with other members of the family. Since the child's unpredictable behaviors can be very difficult to handle, the parents have located an experienced individual to provide care through the respite care program in the community. This individual has had special training to care for children with serious behavior problems.

The third example is of a couple in their sixties with a daughter, aged 30, who is severely mentally retarded. She lives at home and works five days a week at a sheltered workshop in the community. It's necessary for her father to have surgery at a medical center in another state, and her mother very much wants to accompany him. However, there are no other family members available to care for their daughter while they're gone, and the mother is concerned that taking her along would be too much additional responsibility on this trip.

Fortunately, the respite care program in the community was able to help the family locate a young woman who could stay in the family's home and care for their daughter during the two weeks they would be gone. As preparation for everyone involved, the young woman came to the family's home on a couple of evenings prior to the parents' trip. She and the daughter were able to get to know one another better; the parents were able

to fill the care provider in on details; and, importantly, the parents had the chance to see for themselves that their daughter reacted positively to the young woman. Outside of an initial period of anxiety right after her parents left, the daughter did very well during their absence. She was able to continue her life as usual, including going to her job and recreational activities. An additional benefit of this experience was that the parents were able to call on the same care provider again for occasional short-term care - a family support that they had not even been aware of before.

By using the previous 'stories' as samples, describe your own situation and needs for family support.

2. MEETING YOUR NEEDS

Once you've identified your needs, the next step is deciding what kinds of family support you want to use to meet them. It's a process of looking at possibilities.

For example:

To date in Alaska, respite care programs developed specifically to provide occasional, short-term care for families have been organized in half a dozen communities*. The sponsoring organizations are both large and small, new and established, and vary in the services they offer. Some provide short-term care in the family's own home; some in care providers' homes; others have special care facilities in the community. Several of the programs offer a combination of those services.

There are also other programs which provide direct assistance - like routine health care or housekeeping services - to disabled persons in their own homes*. In some cases, short-term care of the disabled person can be an indirect benefit of that program: while the disabled person is receiving medical or household assistance, other family members can have occasional time away.

It may also be that some families don't feel a program is necessary at all - at least for the present. They may be thinking of a less structured approach to short-term care: a list of a few qualified people to call when they need a hand, for instance, and suggestions of ways to familiarize those people with their child (or adult relative) and his/her routine.

We'll be looking at these options more closely throughout the book. The point here, however, is that there are options - something to remember as you begin to figure out what'll work best for you and other families in your community.

Part of the task will also be figuring out if the kinds of support you want already exist in the community, or if you (and others) will have to start them or encourage others to start them.

To explore options in more detail, let's go back to the examples starting

*Currently, those communities include Anchorage, Fairbanks, Juneau, Kenai, Ketchikan, Kodiak, and Sitka.

*Home Health Aide Program and Homemaker Services - See more in chapter 3.

on page 6. The parent who needed day care for her two-year-old was able to get it through an existing program serving the larger community. She first looked for the general support she needed - that is, day care - and then worked to have the day care program stretch to meet the special needs of her child. Integrating disabled persons into an existing program or service can often work very well. Success depends on the attitudes of parents, program administrators and others in the community, plus the time and experience to develop the right approaches.

It's certainly a very desirable option to work for - to put into practice our belief that it's best to include people with disabilities in programs, classrooms, activities and jobs right alongside people who are not disabled.

As any number of educators and others have proven, the benefits of that kind of integration for children are by no means only educational. There's also the benefit of preparing them socially for their lives in the larger community. If we isolate the child with a disability from that larger society, how can we expect him or her to function well within it as an adult? And it's by no means a one-way street: in integrated settings, non-handicapped persons can learn a great deal from their handicapped peers. For those reasons, families are urged whenever possible to locate and/or develop services that integrate disabled and non-disabled people. There are many people with ideas and skills who can help. Sometimes with a little asking around, you can find out about someone who has the experience and knowledge to help stretch regular services to meet special needs.

The second and third examples we looked at earlier involved parents who needed occasional short-term care for their severely disabled children. The first wanted more time for other family members, and the second was faced with a medical emergency. In both instances, parents were able to find what they needed through existing respite care programs in their communities. Those programs had been established by parents specifically to meet families' short-term care needs, to bridge gaps in available care.

Because of the extra demands on families with a severely disabled child (or adult member), parents found they needed help - to add to the care that they themselves could provide. And because of the special needs of severely disabled persons, that help often had to go beyond what is typically thought of as babysitting or day care.

Respite care was developed to meet those extra needs, but to do so in ways that would be as much like the usual family supports as possible. The intent of services like respite care is not to treat families in ways that set them apart from others in the community. Rather, it's to help families continue to be **a part of** their communities, to have the quality of life - as families - that they are entitled to.

If you do decide to start something. . .

Once you've looked into the options

"If a community were going to start a program, my number one question would be: 'Are there parents who will really use it?' Because parents are the strength of the program. . . .

"If it hadn't been for parents, it (the Sitka respite program) wouldn't have gotten started. And it wasn't a large group, but a few really interested ones. . . ."

Mary Lee Wright
Respite care program director
Sitka, Alaska

and possibilities for family support in your community, it may be that you and others will want to start a service or program (formal or informal) to meet your needs.

Here are some things you'll probably want to keep in mind:

While it doesn't take a big organization to put together the kind of short-term care we've been talking about, it does take a group of at least a few interested people willing to work to get the project off the ground - whether it's a full-scale program or something less involved. And most people who've been involved agree: parents and families who need the support should be active members of that group. They're the ones best qualified to say what will and won't work for them. Parents and other family members can, in fact, as they've done in some communities, start their own organizations to develop and provide family support services. Or, as in other cases, there may be an organization already in place in the community which would work with families to provide the support services.

To begin with, it's probably a good idea to get together with other parents and family members who might be interested in services like short-term care. That would tell you if, in fact, there are people in the community who would use the service. If there are, it could help you find a core group of people to work with.

If your community is fairly small, chances are you already know who most of the interested people are. It's just a matter of setting a time and place and contacting them. If your community is

larger (or has a lot of people moving in and out), you may want to put a notice in the newspaper, on a community bulletin board, or maybe put a community service message on the radio. All of that can be done for free. It doesn't have to be anything elaborate - maybe something like this to start with:

Do you need someone to care for a disabled family member while you do shopping, go to a medical appointment or take care of other family business?

Would you like to meet with other parents and family members interested in having short-term care for their children and adult relatives who are disabled?

If so, you're invited to an informal meeting (date), at (time), at the (place). For more information, call (name and phone number of a contact person).

In addition, you could contact your school principal and ask if that same notice (or a short letter) could be sent home to parents of disabled children in the school district. You may very well have other ideas about getting the word out - maybe through an infant learning program, day care center, public health nurse or other sources. (You may want to include some of those people at your meeting too.)

The gathering itself can be an informal one, with people sharing their stories and experiences about family needs. That approach can certainly lead to an understanding of the kinds of support families are looking for. If it seems appropriate, someone can serve as discussion leader, and someone else can record the main points of the meeting. Whether or not the group continues to meet and/or selects a steering committee or officers is, of course, up to that group.

Once people in the community have decided that (1) Yes, they need and want short-term care for family members, and (2) Yes, they are willing to commit time to developing that service, they need to answer another very important question:

What kinds of care can realistically be provided in the community - given the resources (people, time and money) available?

To answer that, it should help to look more closely at some of the different kinds of family support services that are being provided around the state and elsewhere.

Pat Welsh, Sitka, AK, with Ronnie (left) and John Paul. The Welshs were among the founders of the respite program in Sitka.

A CLOSER LOOK AT RESPITE CARE

In communities throughout the country, including several in Alaska, a service called respite care is available to families who have a disabled child or adult member. The service provides a trained person, usually called a respite worker or provider, to care for the disabled person while parents or other family members take care of family business, medical appointments, have an evening out or a needed vacation. "Respite" literally means "a break" - so respite care isn't limited to times when there's an emergency in the family. It can be used for a variety of legitimate reasons - including recreation and relaxation for family members. In most programs, respite care can be provided for periods of time ranging from just a few hours to three or four consecutive weeks.

Here's how a couple of families in Alaskan communities use respite care as a support service:

Sharon Mattingly lives in Fairbanks with her husband and three children: Bart, 10; Regan, 4; and Whitney, 3. Bart is a child whose ability to learn is severely impaired and who is also hyperactive. He requires a very strict routine throughout the day, as well as constant supervision. With Bart, you have to take each task step-by-step. His mother explained:

"You have to go over each thing Bart does. Things that normal kids his age can do on their own - how to eat properly, how to get dressed, to bathe. . .You have to be there to supervise just about everything he does. And there's not much room for flexibility in the routine. . .There's really no time for the other kids - or for yourself. . .Sometimes I feel they (the other children) are being cheated because Bart does require so much of my time. . ."

Bart is also a very impulsive child. He often uses "attention-getting behaviors, temper tantrums and outbursts, seeing

"Ten years ago, nobody had ever heard of respite. It's a pretty new concept that I think has come with an awareness of the handicapped person as a person and the needs of the families.

"It's no longer that you don't tell anybody (about having a handicapped child). . .People are much more willing to accept it for themselves.

"And all of a sudden it's 'Hey, if I'm going to have this child, this person, I'm going to have to have some kind of something to augment myself, to keep me going,' 'cause it's real easy to turn inward and think 'Well, I'll just cope with this myself,' and become a martyr-type person."

Jane White
Parent of a handicapped child
Kenai, Alaska

how far he can go with you. . ." And for that reason the usual child care routes are not open to Bart. Prior to moving to Fairbanks, the Mattinglys lived in Atlanta, Georgia, and Bart had been to "just about every day care and private (child care) home in the county," Sharon said. And all of them without success. As far as child care is concerned, "there has to be a trained person who can understand and handle Bart. . ."

For the Mattinglys, that trained person has been provided through the respite care program run by the Fairbanks Rehabilitation Association. The Mattinglys use the program to have Bart cared for, either at their home or at a respite center, while Sharon and the other kids or Sharon and her husband have some uninterrupted time together. As she put it, "It gives me time to do things with the other members of my family. And it helps me to be a better parent to all three of my children."

Jane White, who lives in Kenai, is the mother of three children, including a daughter, Jenny, age 11, who is severely disabled and whose behavior can also be unpredictable and difficult. The Whites have used the respite care program in their community to allow them the opportunity for vacations:

"It gives us time to be a family in a more normal-type way - like going on a vacation. If we had Jenny with us, probably 50% of my time would be spent coping with Jenny. . .It gives my other children a chance to see their parents in a normal relationship. The

other kids in the family need the respite too. . .

"We've taken two vacations without Jenny along, because she is a real handful to try and take on a plane - no way. She'll sit about 15 minutes and then she's done sitting. . .It's gotten so it's not worth going if we have to take her on the plane. If we didn't have respite, it would be very difficult to find somebody who would be willing to take care of her day and night for that long a time. I don't know where you'd find somebody like that. . . especially for kids with severe disabilities. . ."

In Kenai, the Whites and a number of other families use respite care sponsored by the Central Peninsula Community Mental Health Center. Along with other parents, Jane serves on an advisory committee for respite and other programs for handicapped persons sponsored by the Center.

There are three kinds of respite care that are most common: (1) respite provided in the family's own home; (2) care provided in a respite worker's home; and (3) center-based respite, which is care provided at a central, out-of-home location. We'll look at each of these in more detail.

RESPITE CARE IN THE FAMILY'S HOME

People who use in-home respite care point out that it has some real advantages as a family support. First of all, it gives them peace of mind knowing that someone who is qualified - familiar with handicapping conditions as well as emergency first aid techniques - is caring for their child or adult relative **and** in the family's own home. Many parents feel the familiar surroundings are important for their child; they can be equally important for a disabled adult in the family, particularly an elderly family member.

One parent pointed out that in-home respite can be especially comforting to new parents of a handicapped child. Because it's so much like other kinds of in-home child care often used for very young children, there isn't an "institutional" feeling to the support - a feeling that could be threatening to new parents. A parent of two handicapped children who is active in a respite program, put it like this:

"When parents are first coming to grips with the fact that they have a child who is handicapped, and they have made their decision to keep the child at home, anything having to do with leaving the child someplace outside the home can be threatening or seen as negative. . .When the child gets a little older, it's usually easier for the parents. There are more models for out-of-home care as the child gets older - day care centers, pre-schools and regular school. . ."

There are other reasons why in-home respite can be a plus. When parents have only a limited time to run errands during

Beth Godes, Kenai, AK, with daughter Mariah. The Godes' use in-home respite care as a family support.

a 'respite,' it can be more efficient to have the respite worker come to the house than to spend extra time transporting their child elsewhere. When parents are going to be gone overnight, it can also be more convenient to have the respite worker come to their home. That can eliminate having to prepare for a child's overnight stay someplace else. There can also be other considerations which make in-home respite advantageous for a family. As one parent of a twelve-year-old who uses a wheelchair said, "To load Jylle up in the car is the problem. We're fine once we get there - it's getting in and out of places that's hard."

In that family's case, respite care has meant a great deal more freedom and flexibility - not only for the parents, but also for their daughter. Respite care, according to her mother, has been ". . . one of the major turning points in trying to direct Jylle to making her own decisions." With respite care, Jylle can express a choice more often about what she'd like to do. Sometimes, for example, if other members of the family want to be involved in certain recreation activities, she can choose to do something else. As her mother put it, "Sometimes it can be more fun to stay at home and play with somebody than sit in the hot sun and watch other people do things you can't do. . ."

In addition to its convenience, the in-home respite can have another benefit for families: it can provide the opportunity for all the children in a family to be cared for together. The brothers and sisters of a

"It fills up the spaces between what my daughter's day program can do for her and what our family can do for her. By itself, it's not any one big thing. It's several little things. But our family life, and our daughter's life, is much better because of it."

Parent of a handicapped child

disabled child can be cared for at the same time and at the same place as their sibling. Many parents are quick to point out how important that is to the family.

One mother of three children - two boys with handicaps and a non-handicapped daughter - described her feelings when a respite program did not make an allowance for her daughter to remain at home with the boys during respite care:

"The security of knowing that it (respite) is there makes us a whole lot more relaxed all the time."

Parent of a handicapped child

"We do everything together. When we go skiing, everybody goes, for example, and we've spent a lot of years teaching our daughter that there was nothing wrong with her brothers - that they were just different. It was real hard, then, to explain to her why she couldn't stay at home with her brothers when the respite worker arrived. Plus, the worker was someone she knew and liked, so she actually felt she was being denied something special. . ."

Unless the disabled child's condition is so severe or the demands of the other children so great that they could interfere with proper care, it would seem to be most natural and in the family's best interest to keep the children together. Most in-home respite programs in the state make provisions for caring for siblings. Individual respite workers can choose if they want to care for siblings or not, and if they do, they are paid an additional amount by the family.

A note of caution: While siblings can be a big help by providing information to

respite workers and by being reassuring to their brother or sister who's disabled, one respite administrator pointed out that there can also be problems with the care of siblings. She expressed a great deal of caution: "Some of our workers have found that the non-handicapped kids require more care than the handicapped kids. . . Ultimately, it increases the risks and liabilities for the respite provider." In her program, siblings can be at home while respite is being provided, but the respite worker is not responsible for them.

While the issue undoubtedly has pros and cons, what's best with regard to sibling care will probably depend on individual family situations. Programs should be flexible to meet families' needs, but without risking health and safety.

SOME EXAMPLES OF HOW AN IN-HOME RESPITE PROGRAM WORKS

As one parent put it, "Even if you can afford to pay for care for your handicapped child, a lot of times you can't find anybody to help out. . ."

That's exactly the situation a couple of parents in Sitka found themselves in. Attempts to find teenagers to care for their severely handicapped kids usually didn't work. Because of the special needs of the children, either the teenagers themselves didn't feel comfortable, or the parents of the teenagers were uneasy. Adult relatives in the community had jobs and other commitments, and while they were willing to help out when they could, their available time was limited. The result was little or no break for the parents - especially for the parents together, since one or the other almost always had the responsibility for child care. It also meant real difficulties in tending to other family matters, like the activities of the other kids, school functions, meetings, and church activities.

So it was that respite care got its start in that community - primarily through the actions of parents who needed it. That was in 1980, and with technical assistance and funding from the Governor's Council for the Handicapped and Gifted and the state's Division of Mental Health and Developmental Disabilities, an in-home respite care program was developed. State funds were made available to an existing group, Sitka PACS, Inc. (Parents Association for Citizens with Special Needs) for the support of the program.

Sitka-PACS, Inc. is a non-profit organization made up of people who are interested in promoting the welfare and rights of people who are disabled. Those interested people include parents, teachers, medical professionals, business people and others.

Interested parents and others in Ketchikan have formed a similar organization called KAPPS (Ketchikan Association of Parents for People with Special Needs) to provide respite care in their community.

In both instances, the respite care programs have small steering committees - four or five people - to oversee their programs. Approximately half of the committee members must be parents of persons

Marcie Hiiai, chairperson of the Sitka respite program steering committee. The five-member committee includes parents or other relatives of disabled persons, as well as other interested members of the community.

with disabilities (or other adult family members living with a disabled person). The remaining members can be other interested persons from the community.

The steering committee develops guidelines for the respite program, develops and keeps track of the program budget, hears and evaluates suggestions and complaints from families. In short, the committee keeps an eye on the way the whole program is working.

The steering committees in both of these communities hired a part-time director for their respite programs - someone to spread the word to families and to coordinate the services. Those individuals, a former special education teacher in one community, a former occupational therapist in the other, are paid for approximately ten hours of work per week.

In general, these two respite programs operate much like other in-home respite programs in the state and elsewhere. **Very basically, the programs:**

(1) Provide training for people in the community who want to become respite care workers; and

(2) Match those respite providers with the families in the community who need short-term care.

As parents and others have pointed out, coordinating a respite program is "not a bookkeeping function."

It takes "knowing how to work with families, when to let families call the shots. . .and good organizational skills, especially if it's one person doing the job."

Sample Program

Although in-home respite programs do differ in the details of their operations, here's a closer look at a sample program:

The respite care workers (also called providers) in this program are people of various ages and interests from

throughout the community. They include both men and women. Some are young adults, some are retired persons. They are both married and single; some are working at other jobs part of the time, others are involved only in the respite program. Overall, they represent a good mix of people from the community.

Under this sample program, respite workers are considered self-employed individuals who are hired from time to time by families to provide short-term care. For the most part, families choose the workers they prefer from people in the community who have completed the respite training. Families make their own arrangements for respite care with those workers and then confirm the arrangements with the program director. The director is responsible for most of the record-keeping, including the amount of respite care provided to families, the financial records, and so on. Families share the cost of care with the respite program, which has state funding to assist with its operation. If a family can't afford to pay its share, the cost can usually be covered in full by the program.

Through the respite program, people interested in becoming care providers are taught the basics about such things as:

Handicapping conditions

Special needs of families with disabled children/adults

How respite care fits in with other services for disabled persons

Treating medical emergencies

Behavior management techniques

Home safety and accident prevention

The basics of communication techniques such as sign language

How to help with dressing, grooming and toileting

Appropriate leisure time activities for persons with disabilities

How to give medications

Nutrition and feeding

Lifting and carrying disabled persons

In addition, care providers get a lot of helpful information directly from the families who use respite care. In this sample program, a provider who is interested in working for a family meets with them in their home to talk about specific needs, and the requirements and routines of the person in the family who will be cared for. That meeting gives the family and the provider a chance to get to know one another better and to decide if they think they can work well together.

First things first, however. Before a family gets involved in selecting and working with respite providers, the first step is to meet with the program director. At that initial meeting, the family - parent(s) or guardian(s) - complete some

forms which are used to help the director and the providers do the best job for the family. (See "Application for Respite Care" and "Information Summary," pages 25-33). These procedures are common in some form to most of the respite programs in the state.

After that meeting, the director can help the family locate prospective care providers. Ideally the family can choose a couple of providers to work for them as the need arises. Providers can certainly work for more than one family as schedules allow.

In addition to the application forms and information summary, families must also complete an 'update' form each time they want to use respite care. That form (see sample on page 35) is used to make sure respite workers have current information on conditions that could change every time care is provided - general health of the disabled person, behaviors, medications, and so forth. Also included is a sample acknowledgement form which care providers must sign to indicate that they have read the information summary about the person receiving care.

SOME SAMPLE FORMS

On the following pages are some samples of forms which are often used in respite programs. In many cases, the same forms are used for respite in the family's home, the provider's home, or for center-based care.

The forms can be very useful in helping providers do the best job possible.

For Respite Care Programs:

"By the time most parents get to respite, they've gone through so many forms, so please make them as simple and as painless as possible."

For Parents:

"If you're going to entrust your child to them (respite workers), you surely can give them the information they'll need."

Ludy Jacobs
Parent of a handicapped child
Anchorage, Alaska

The forms are kept at the family's home and/or the respite office (or other central location), and respite workers must review the information before providing care. In some programs, most of the information about the person to be cared for is left at the family's home where it can be readily available to providers. In the case of the 'information update,' the provider can have the family complete that form at the time respite is to be used.

Keep in mind that the particular style and wording of the forms - even the information you ask for - can vary a good deal, depending on what fits the needs of your community and your people.

The forms that follow include:

Application for Respite Care (pp. 25-26)
Provides basic information about the family

Information Summary (pp. 27-33)
Provides more detailed information about the person to be cared for which is used by providers; helps providers do their best for the family

Acknowledgement (p. 34)
Confirms that the provider has reviewed the above information

Information Update (pp. 35-36)
Filled out each time respite is provided -in case important information changes

Safety Checklist (p. 37)
Confirms that home is safe for care

Emergency Phone Numbers (p. 38)
Posted in home for care providers' information

Evaluation Sheet (p. 39)
Used by families to let the program know the quality of care received

Sample Form

APPLICATION FOR RESPITE CARE

I. Person requesting care:
Name: _____
Address: _____
Phone: _____ (home) _____ (work)

II. Homeowners/tenants liability insurance
(Insurance company and policy number):
_____

III. Name of person to receive care: _____
Age: _____ Birth date: _____ Handicapping condition: _____
_____

IV. Information about the person who will receive respite care.
(Please x where appropriate):
1. _____ takes medications (for what - please explain) _____
_____
2. _____ has seizures
_____ controlled
_____ uncontrolled
3. _____ can walk
4. _____ has some speech
5. _____ is toilet trained
_____ fully
_____ partially
6. _____ feeds self
7. _____ dresses self
8. _____ takes a nap in the:
_____ a.m. _____ p.m.
9. _____ is allergic (please explain):
_____
10. _____ attends school, program, workshop (please give name and schedule):
_____
_____

V. Emergency contacts:
Name: _____ Relationship: _____
Address: _____
Phone: _____ (home) _____ (work)
Name: _____ Relationship: _____
Address: _____
Phone: _____ (home) _____ (work)

VI. Information about other persons living at home:

	Name	Relationship	Age	Sex
1.				
2.				
3.				
4.				
5.				

25

APPLICATION FOR RESPITE CARE
(continued)

VII. Care preferences:

1. Please list any age, sex or other preferences you would have for a care provider:

Age: _____ Sex: _____ Other: _____
_____

2. I would prefer that care be provided at:

_____my home
_____provider's home
_____other respite facility
_____other (please explain):
_____

3. I am_____able_____unable to pay for a portion of the cost of care.

_____I am willing to do some volunteer work for the program as my portion of the cost.

4. I will usually need a provider:

_____mornings _____afternoons _____evenings
_____weekends _____overnight _____emergencies
_____don't know for sure

VIII. Physician of person to receive care:

Name: _____
Address: _____
Phone: _____

IX. Dentist of person to receive care:

Name: _____
Address: _____
Phone: _____

X. Medical insurance of person to receive care:

Company: _____
Policy No.: _____

INFORMATION SUMMARY

1. POSITION
   - In crib or bed only ( )
   - Holds head up ( )
   - Rolls over ( )
   - Sits supported ( )
   - Sits unsupported ( )

   Special equipment:

   _____
   _____
   _____

   *Prescriptive program goal:

   _____
   _____
   _____

   Procedure:

   _____
   _____
   _____

*Prescriptive program goals refer to accomplishments which the disabled child or adult and his/her family are working on, often with help from a teacher or other resource person. The "procedures" refer to the ways they are going about achieving those goals. For example, in one family an older child who is being toilet-trained is allowed to have graham crackers as a snack throughout the day, but only if his pants are dry. This is important training for that child and the family, so someone who would be caring for him should know about that plan and just how to follow through with it.

2. MEANS OF MOVEMENT
   - Makes no attempt to move ( )
   - Moves about on floor by:
     - Rolling ( ) Scooting ( )
     - Crawling ( ) Other ( )

   Explain: _____
   _____
   _____

   - Pulls self up to stand ( )
   - Walks with help ( )
   - Walks alone ( )
   - Walks up ( ) down ( ) stairs
   - Uses walker ( )
   - Can sit in wheelchair ( )

   Special equipment: _____
   _____
   _____

   Prescriptive program goal: _____
   _____
   _____
   _____
   _____
   _____
   _____

   Procedure: _____
   _____
   _____
   _____
   _____
   _____
   _____
   _____

Sample Form

INFORMATION SUMMARY
(continued)

3. TOILETING

In diapers ( )
Bladder control ( )
Bowel control ( )
Goes with assistance ( )
Trip trained ( )
Toileting schedule: _____
_____
_____
Goes independently ( )
What is the toilet signal? (symbol/word)?
_____
Prescriptive program goal:
_____
_____
Procedure: _____
_____

4. FEEDING

Bottle ( )
Drinks from cup ( ) glass ( )
With assistance ( )
Without assistance ( )
Finger feeds self ( )
Fed with spoon ( ) fork ( )
Uses spoon ( ) fork ( )
With assistance ( )
Without assistance ( )

FEEDING cont'd.

Independent at table ( )
Special diet ( )
Explain: _____
_____
What is the signal (symbol/word) for hungry?
_____
Thirsty? _____
_____
List any eating problems and procedures for handling them:
_____
_____
_____
_____
_____
Special equipment: _____
_____
Prescriptive program goal: _____
_____
_____
Procedure: _____
_____
_____
_____
_____
_____

INFORMATION SUMMARY
(continued)

5. DRESSING

Can dress independently ( )
Can dress self with help ( )
Explain: _____
_____
_____

Cannot dress self with help ( )
Explain: _____
_____

Can undress independently ( )
Can undress self with help ( )
Explain: _____
_____
_____

Cannot undress self with help ( )
Explain: _____
_____

Special equipment: _____
_____

Prescriptive program goal: _____
_____
_____

Procedure: _____
_____
_____

6. HYGIENE

Bathing: shower ( ) bath ( )
Washes independently ( )
Fears water ( )
Cannot wash self ( )
Can wash with help ( )
Explain: _____
_____

Independent in toothbrushing ( )
Does ( ) does not ( ) cooperate with toothbrushing
Brushes teeth with help ( )
Explain: _____
_____

Shampoos hair independently ( )
Shampoos hair with help ( )
Explain: _____
_____

Allergies to shampoo ( )
Explain: _____
_____

Combs/brushes hair independently ( )
With assistance ( )
Explain: _____
_____

INFORMATION SUMMARY
(continued)

HYGIENE cont'd.

If female, does she menstruate? Yes ( ) No ( )
Independently attends to menstrual needs ( )
Needs help with personal hygiene related to menstruation ( )

Explain: _____

_____

_____

Special equipment: _____

_____

_____

Prescriptive program goal: _____

_____

_____

_____

Procedure: _____

_____

_____

_____

7. VISION

Blind ( )
Blind, one eye L ( ) R ( )
Some vision ( )
Good vision ( )

Glasses, special equipment: _____

_____

_____

Prescriptive program goal: _____

_____

_____

Procedure: _____

_____

_____

8. HEARING

Deaf ( )
Deaf, one ear L ( ) R ( )
Some hearing ( )
Normal hearing ( )
Special equipment: _____

_____

_____

Prescriptive program goal: _____

_____

_____

_____

Procedure: _____

_____

_____

INFORMATION SUMMARY
(continued)

9. SEIZURES

None ( )

Uncontrolled ( )

Controlled with medication _____

Explain: _____

_____

_____

10. LANGUAGE

Normal development ( )

Smiles, laughs ( )

Makes random vocalizations ( )

Imitates sounds ( )

Receptive language:
average ( ) poor ( )

Follows single concept commands ( )

Talks in two-three word sentences ( )

Indicates needs by crying, pointing, etc. ( )

Explain: _____

_____

Uses names of familiar objects

List: _____

_____

_____

_____

_____

Uses sign language ( )

List: _____

_____

_____

Uses a language board ( )

List: _____

_____

_____

Other: _____

_____

_____

Speech is unimpaired ( )

Speech is difficult to understand ( )

Prescriptive program goal: _____

_____

_____

Procedure: _____

_____

_____

11. BEDTIME

What is typical bedtime hour? _____

Rising Time? _____

Nap Time? _____

What special routine is followed at these times? _____

_____

INFORMATION SUMMARY
(continued)

BEDTIME cont'd.

Prescriptive program goal: _____

_____

_____

_____

Procedure: _____

_____

_____

12. HEALTH PROBLEMS

None at present ( )

Hyperactivity ( )

Frequent upper respiratory infections, etc. ( )

Other respiratory ailments, (asthma, etc.) ( )

Explain: _____

_____

_____

_____

Heart defect ( )

Explain: _____

_____

Orthopedic difficulties ( )

Dental problems ( )

Allergies ( )

List: _____

List all serious illnesses if recent enough to be of concern: _____

_____

_____

_____

List all medications currently given or prescribed, including dosages, the purpose and where medications are kept:

_____

_____

_____

_____

_____

_____

13. SOCIALIZATION

Enjoys being held and played with ( )

Plays cooperatively with others ( )

Plays alone ( )

Prefers to be left alone ( )

Handles frustration by: _____

_____

_____

_____

Responds to change in routine by: ____

_____

_____

_____

INFORMATION SUMMARY
(continued)

SOCIALIZATION cont'd.

Presently, are there behaviors which you are trying to modify?

List: _____

_____

_____

_____

_____

Method of correction: _____

_____

_____

_____

_____

_____

14. FAVORITE ACTIVITIES

List: _____

_____

_____

_____

Favorite games/toys: _____

_____

_____

_____

Other: _____

_____

_____

15. FAVORITE TREATS

List: _____

_____

_____

_____

_____

_____

_____

_____

16. NOTES ABOUT SIBLINGS

_____

_____

_____

17. NOTES ABOUT 'HOUSE RULES'

_____

_____

_____

_____

18. DISCIPLINE/DISCIPLINARY ACTIONS*

_____

_____

_____

_____

*NOTE: In most respite programs providers are specifically prohibited from using physical forms of punishment, even if parents approve.

Sample Form

RESPITE CARE PROVIDER'S ACKNOWLEDGEMENT OF RECEIPT OF INFORMATION

I, _____, a respite care provider for _____
(Provider's name)

_____ Respite Care Program, have received the Information
(Name of program)

Summary for _____.
(Name of person receiving care)

I have carefully read the same.

I have reviewed the information with _____,
[Name(s) of parent(s)/guardian(s)]

_____parent(s)_____guardian(s), and have discussed any special concerns and have had all questions answered to my satisfaction.

_____ _____
Signature of Respite Care Provider Date

Sample Form

INFORMATION UPDATE

NOTE: It is the responsibility of the family to complete this form prior to the time respite is provided. It must be completed each time that respite is provided.

Name of person to receive care: _____

I. General Health (recent illnesses): _____

_____

_____

_____

II. Behaviors (anything out of the ordinary): _____

_____

_____

_____

III. Habits (changes in naptime, snacktime, mealtime): _____

_____

_____

_____

IV. Medication(s) to be taken by person receiving care:

Name of Medication: _____

Dosage: _____

How is it to be administered: _____

At which times is it to be given: _____

_____

INFORMATION UPDATE
(continued)

V. Where I/We will be during time care is provided: _____

Address: _____

Phone: _____

VI. Physician of person to receive care: _____

Address: _____

Phone: _____

VII. In case of emergency and you cannot reach me, please call: _____

1. Name: _____ Relationship: _____

Address: _____

Phone(s): _____

2. Name: _____ Relationship: _____

Address: _____

Phone(s): _____

VIII. Other comments: _____

_____

_____

_____

I have doubled-checked all the information and it is correct.

_____
Print Name of Parent/Guardian

_____ _____
Signature of Parent/Guardian Date

_____ _____
Respite Care Provider Date

Sample Form

SAFETY CHECKLIST

Please answer all the items listed below:

	YES	NO	COMMENT/LOCATION
Is your home equipped with:			
1. Fire extinguisher			
2. Smoke detector			
3. A working flashlight or other emergency lighting			
4. Telephones			
5. Emergency numbers posted by the telephone			
6. First aid supplies maintained and readily available			
7. Heat source free of flammable or liquid combustible materials			
8. Dangerous chemicals and cleaning materials stored properly (out of reach and/or in locked cabinets)			
9. Firearms and ammunition stored properly (out of reach and/or in locked cabinets)			

I (We) have carefully reviewed the list above. I (We) feel that adequate measures have been taken to insure that our home is free from those and other hazards.

_____

Signature of Parent or Guardian

_____

Signature of Parent or Guardian

Dated _____

Sample Form

EMERGENCY PHONE NUMBERS

Numbers to contact in the event of an emergency. Please post in your home for provider's information.

FIRE ..... _____ _____

POLICE ..... _____

AMBULANCE ..... _____

DOCTOR ..... _____

HOSPITAL ..... _____

HEALTH AIDE OR NURSE/CLINIC ..... _____

RESPITE CARE PROGRAM DIRECTOR ..... _____

POISON CONTROL CENTER ..... _____

Sample Form

RESPITE CARE EVALUATION

Name of person evaluating the service: _____ _____
(Name)

1. Did you feel the service provided was appropriate? Yes_____ No_____

2. If you need respite care again, would you use this service? Yes_____ No_____

3. Would you recommend this service to others? Yes_____ No_____ Why?_____

_____

4. On the following scale, rate the respite care provider, _____

_____ .
(Provider's name)

strong average weak

_____ _____ _____

Why?_____

_____

5. Additional comments:

_____

_____

_____

_____

6. When did respite care service begin?

Date: _____ Time: _____

When did respite care service end?

Date: _____ Time: _____

Colin Scholle, coordinator of the Fairbanks Rehabilitation Association (FRA) respite program. The FRA program includes in-home and center-based care.

SCHEDULING CARE

Once the advance preparations have been taken care of, the family can begin to use the respite program. Again, in the way this sample program is set up, families contact their respite providers directly to schedule care. They also need to call and confirm that schedule with the program director: since state funds are used to support the program, an accurate accounting of the hours of care provided and the number of families served is necessary. The program director is responsible for that accounting.

In some other respite programs, families don't contact care providers directly - unless there's an emergency situation. Rather, they call the program director (or other staff), who in turn contacts the provider and schedules care. In large respite programs, there may be a full-time person available to do that. In other cases, programs rely on an answering machine: families leave their requests for respite, and the part-time director checks those messages each day. The director schedules the care and then confirms it with the family.

In cases where the respite program is a large one, serving many families with many providers, it may be more efficient to schedule care from a central location especially if an accounting of that care (exact number of hours provided and families served) is a funding requirement. In small programs as well, respite directors may feel they can coordinate their programs better if they arrange the care with providers.

As we've said before, there is no one way to handle the program. It's worth considering, however, that having families contact the providers directly can be more in keeping with the usual ways people handle their child care (and other family care) needs. Many people are used to contacting babysitters, day care centers, household helpers - whatever it might be that they need - and prefer making those arrangements themselves. Respite care can be handled in that way too, with the family keeping the primary responsibility for scheduling care.

Another note of caution: There can also be some problems with that approach, according to at least one respite director in the state. Specifically, there may be some parents who will place too many demands on a respite provider - call too often for care or always on too short of notice. Some providers can find it hard to say no to a parent's direct request and, over time, that can lead to at least a temporary burn-out. As the director put it, "Pretty soon you can feel the tension. . . Those situations always end up with the provider eventually refusing to work for that family anymore. . .Providers **will** say 'no' to the respite staff. Staff can also emphasize to the provider when the need for care for a particular family is an emergency or especially important. . ."

It will be up to the families in your community to decide which methods of arranging care will work best for them. The danger is simply in having too much 'program' and too much structure. That can put some people off and make them

reluctant to use the service. A good orientation session for both providers and families may help to minimize problems. Whatever procedures you choose, you'll want to make certain that they increase rather than decrease families' feelings of self-sufficiency and control over their lives.

As far as charging for respite care is concerned, programs handle that differently too. In the sample program, families who use respite pay part of the cost (25%), with the program picking up the rest through its state grant funds.

The respite care providers in the sample program earn $6.00 an hour for daytime and evening care (care provided from 6 a.m. - 10 p.m.). Of that $6, the respite program covers $4.50 and the family pays $1.50. Providers earn $4.00 an hour for nighttime care (10 p.m. to 6 a.m.), with the program paying $3 and the family paying one dollar*. If a family can't afford to pay for care, the total cost can be picked up by the program, with the approval of the steering committee and the director. In this particular program, families pay their share to the provider at the time the care is given. The program pays providers on a regularly-scheduled basis. Providers charge families an additional amount for the care of non-disabled siblings, and the families are responsible for 100% of that cost. (More on funding in a later section.)

*Respite workers in the state currently are paid from $4.00 to over $7.00 per hour, depending on the program.

EXAMPLES OF CARE IN THE PROVIDER'S HOME

In addition to respite care in the family's own home, it's not uncommon for programs to offer care in the provider's home - a relatively easy way of giving families another alternative. While, in general, it's not as much in demand as care in the family's home, having the option available can mean a lot to families. These 'respite homes' have been especially useful when parents have needed care for extended periods of time - maybe because of a medical emergency or a vacation. While respite care can be provided for longer periods in the family's own home as well, it may not be as easy to arrange - to find a provider available to stay in the family's home for a couple of weeks or more. The provider's home can work out a lot better on that score and although, initially, some adjustment to new surroundings would be necessary, the child or other family member would have a consistent, comfortable home environment, often including other children.

There are some other reasons for using care in a provider's home. Parents in Sitka, for example, tend to use that option for shorter-term activities. Families occasionally use a provider's home if they are going to be entertaining, or when they need to do cleaning or other chores at home that require their full attention.

The providers whose homes are used for respite do not have to be involved in other parts of the respite program, such as providing care in the families' homes.

And, of course, they can - like any other respite provider - indicate a preference for caring for persons of a certain age group, severity of disability, and so on.

Providers offering care in their homes must, however, complete the respite program training - like all other providers. Importantly, homes used for respite must be safe and otherwise appropriate for that purpose. While there are no particular licensing requirements for respite homes as such, some programs use the state's requirements for foster home licensing as guidelines. Those requirements are available from the state's Division of Family and Youth Services.

RESPITE CARE IN OTHER SETTINGS

In addition to the kinds of 'in-home' respite we've described, there's also what is called center-based respite - that is, care provided outside of the home, at a center or other facility in the community.

There are a few communities in the state which are currently providing families with center-based respite. Here are a couple of different approaches. The first gives an example of how a respite program has been 'mixed in' with some existing services; the second is strictly a respite facility serving a larger community.

In Juneau, respite care is provided at the St. Jude Center, a facility which is operated by a non-profit corporation and offers:

1. a mainstreamed special education pre-school program for handicapped and non-handicapped youngsters;
2. an infant learning program for children, birth to three, who have handicaps, and;
3. the respite care program.

The center is open to provide respite care 24 hours a day. There is space for four to five children to receive respite at any one time, and care is provided on a first-come, first-served basis. Families can schedule care in advance (for a maximum of three consecutive weeks) or they can call on the spur-of-the-moment to see if space is available. Detailed information about the children using the respite program is on file at the center and is updated as necessary.

During the day, children who are receiving respite care are included in day care activities with the other children (when it's appropriate because of age and other factors). Other activities are available for older children who are receiving respite. (As with most respite programs, however, parents cannot use it for child care while they work. That is considered day care, and parents must enroll their child in the day care program and pay for that service. Respite care in this program is free, and is intended as a break for parents when they need to attend to other matters or have some time for themselves.)

The center's full-time registered nurse serves as coordinator of the respite program. During the day, she is at the center and oversees the care of the children in

An effective option is to include children with handicaps in programs with non-handicapped youngsters.

Joan Jordan, director of the St. Jude Center, Juneau, AK, which provides center-based respite.

that program. She is also on-call in the evenings in the event of medical emergencies.

When the day care program is over at 5:30 p.m., respite providers are on duty to keep respite care available all night. Bedrooms and living areas are available for the respite service. Providers (usually one per shift) work eight hours, 4:00 p.m. to midnight and midnight to 8:00 a.m. Parents can, provided there is space available, drop their child or children off for a couple of hours, for the entire evening, or overnight. With advance arrangements, children can remain at the facility for extended periods - up to three weeks if necessary. In cases of short-term care, if space is available, a non-handicapped sibling (or even siblings) can be cared for along with their brother or sister.

In addition to the fact that the center is open 24 hours a day for respite, some parents point to its location - across the parking lot from the hospital - as a "great plus" for the program.

One Juneau parent, Sue Behnert, described her feelings about the location:

"He (her young son Carl) was really failing. He was losing weight; he was turning blue quite a bit of the time. He wasn't eating. So there were times when I wouldn't have gone anyplace unless I knew he was where he could be observed by the nurse. I knew if something had gone really sour with him, she would have picked him up and marched him right over to the pediatrician or to the emergency

"I have always felt that respite was set up as a break for parents of the families who are 24 hours a day, 30 days a month, 365 days a year with these kids. And it's just to give them a chance to get away. And the child too. As we've been with Erin longer, I realize she needs to get away from us too.

"We do everything with Erin. It's Larry and I and Pat. It's the three of us. Mostly there aren't other people, and as neat as our friends are, they don't ever say. . .'Could Erin come and do this or that with somebody?' She just doesn't have that."

Joan Carroll
Parent of a handicapped child
Juneau, Alaska

"We can all sense when we've been around Erin too much, 'cause we're all barkin' at her - and at each other."

Larry Carroll
Parent of a handicapped child
Juneau, Alaska

room, which is across the parking lot. Having that skilled medical person there was really important to me for about a year. . . .There are children who have seizure disorders and multiple handicaps who can benefit by having a medical person available."

Even in cases where a child doesn't have a serious or chronic medical problem, parents still feel having medical care nearby is important:

". . .I feel really secure with Erin - and I think I may be overly protective many times - but they're really close to the hospital and I think medical help has to be available for these special kids. Even though Erin doesn't have convulsive disorders, she doesn't have anything that's medically wrong with her. . .But I just feel safer. . .You don't know what can go wrong, but so many things do go wrong with these kids. . .It's nice to know it's there."

While some parents have said that having respite care available in their homes would be a nice addition to the center-based program, the decision to go with the center "got down to the basics of economics," according to St. Jude board member Larry Carroll.

The building, as well as the day care program and educational staff, were in place when the respite program was added - an economical approach which may or may not be available in your community. If there is a day care center or other facility in your community which would have some space available for respite services, it could be an option worth looking into. Or you might be able to share a facility with another organization - maybe use it for respite during evenings and overnight.

Because of its function as a day care center, a facility like St. Jude's must be licensed accordingly by the state. The building itself must meet necessary construction and safety requirements, as well as requirements related to the number and age of children who can be served. Additionally, the necessary insurances must be kept up-to-date on the building and employees for liability purposes.

Center-based respite care does not, of course, have to be part of a larger facility and program. The respite program can operate its own facility - provided the right kind of resources are available. In Fairbanks, the respite program rents a two-bedroom apartment where care can be provided on a 24-hour a day basis. Continuous respite is available for up to four weeks.

The respite apartment, located in one of the apartment complexes in the community, can serve three people at any one time. By contacting the respite care office, families can request care at the apartment, rather than at their own home or a provider's home.

While center-based respite can be very useful by providing opportunities for spontaneous respite (i.e. dropping a child off at the center if space is available) and

for extended care (overnight and longer), there is a **note of caution** to keep in mind. A couple of respite directors pointed out that too long a stay at the center can cause some serious adjustment problems for a child. Most respite programs limit care to three or four consecutive weeks maximum, and some directors feel that may be too long. As one director said, "In 10 to 12 days at the center, you can begin to see changes in behavior; after 2½ weeks, forget it. . ." She added that much of the problem stems from the fact that the population can change so often at a center - "There may be eight kids or one kid. . . " and it can be very disorienting to a child. If your community chooses to include center-based care, you'll want to be aware of the potential for those kinds of problems.

THE IMPORTANCE OF THE PROVIDERS

No matter what kinds of respite care you provide, much of the success of the experience - and the program as a whole - will depend on the respite providers and their ability to do the job well. One parent of a handicapped child described her feelings about the service this way:

"You can go out somewhere and not have to worry. You can go somewhere and not feel you have to call home to see how things are going, because you know you have someone who is really competent in your home . . .That's the difference between when I have a respite worker and when I have a regular babysitter. And I always hire two babysitters to take care of my kids if I leave all three of them. I hire two babysitters, but one respite worker. . .I feel real comfortable with the respite worker. Whatever comes up, they'll be able to handle it. . ."

Many other parents have likewise pointed to their trust in the respite providers as the key to the service. And that trust comes, in large part, from the fact that providers receive training to prepare them for working with families, especially with family members who are disabled. Although different respite services prepare their workers in different ways, generally there is a structured training program, including information on medical conditions, disabilities, behaviors, first-aid techniques, family needs and so on. Some of these training programs last for a few hours, others for a full day or as much as a weekend. The length of the training - and how much information is included - should depend on the needs of the families who will be using the service, and the backgrounds of the providers. Each community will have to look at those factors and come up with its own program.

However, there are certain guidelines to keep in mind. You will want respite providers to be familiar with the disabling conditions of the people they'll be caring for. They should be trained to handle medical emergencies and take care of such things as proper feeding or lifting if

Fairbanks Rehabilitation Association (FRA) respite provider Liz Smith (right) with program participant Holly Murray.

family members require those kinds of help. There may be certain behavioral problems, and the respite workers should have information on dealing with those. Beyond that, look at what the specific needs of the families in your community are and work from there.

One community has worked out a weekend training session which involves teachers, medical professionals and parents.

The session goes something like this:

(1) On Friday night, the respite director fills the prospective workers in on what respite care is all about, how the care is provided, how much and when the providers get paid, the paper work that has to be filled out, and other details about the program.

(2) On Saturday, the school nurse or other trained person gives a session on emergency medical treatment. Following that, the special education teacher presents information on the basics of sign language, on ways to handle difficult behavior, and how to follow through with special learning and behavior programs that the school and parents may have set up for a child.

The last session on Saturday involves a group of parents of handicapped children in the community. The parents have the chance to explain what they think is important for the respite workers to know and do. This session gives the new workers a chance to ask the parents questions about the care of their children (or other family members).

The parents also have a chance to share information about the emotional needs of families with handicapped children. Parents explain, for example, the grieving process that many families go through after the birth of a handicapped child. If the respite workers are sensitive to those kinds of feelings, they can offer much more in the way of support to the family. For both the workers and the parents, this session is the most popular of the entire training.

(3) On Sunday, there is a follow-up on sign language and instruction on special aspects of nutrition and hygiene for people with certain disabilities. There's also information on such things as the proper ways of lifting and transferring someone who is physically disabled.

In addition to the information already covered, the new respite workers get a handout on safety in the home. And they must complete an 8-hour first aid course offered through the community's fire department. Both the weekend training session and the first aid course are requirements. Once they've been met, the new respite workers can begin to provide care for families.

On the next page is a sample training schedule from another respite program. Remember that the training can be tailored - including shortened - to better meet your needs. We've used the term 'respite director' in the sample. If it were more appropriate to your situation, a 'parent discussion leader' or other person could be substituted.

Sample Form

RESPITE CARE TRAINING PROGRAM

Friday

Time	Topic	Resource Person
7:00- 8:00 p.m.	Overview of Handicapping Conditions including a slide show presentation*	Respite Care Program Director and Special Education Teacher
8:00- 8:30 p.m.	Overview of Respite Program	Respite Director
8:30- 8:45 p.m.	Meet a Respite Provider - first-hand approach to what job is like	Selected Provider
8:45- 9:45 p.m.	Film Related to Attitudes toward Disabled Persons - followed by discussion**	Respite Director

Saturday

Time	Topic	Resource Person
8:30- 9:30 a.m.	Introduction to the Families of Developmentally Disabled/What families feel and experience having a child with a disability	Special Education Teacher
9:30- 9:45 a.m.	Break	
9:45-10:15 a.m.	What Families Expect of a Respite Care Provider/ How parents feel about leaving their child with someone else	Panel of Parents
10:15-10:45 a.m.	Film and Discussion	Respite Director
10:45-Noon	About Prescriptive Programs	Special Education Teacher
Noon-1:00 p.m.	LUNCH	

*You may want to check with your special education teacher(s) and other resource persons for slide shows and other materials. Other respite care programs - addresses listed at back of book - will have leads on materials.

**A "Resource Book of Films" is available free-of-charge from the Governor's Council for the Handicapped and Gifted (address at back of book). Also check your school and/or library.

RESPITE CARE TRAINING PROGRAM
(continued)

Saturday (cont'd.)

Time	Topic	Resource Person
1:00- 2:00 p.m.	Child/Behavior Management	Resource Teacher
2:15- 3:00 p.m.	Home Safety/Accident Prevention	Fire Department Inspector
3:00- 3:15 p.m.	Break	
3:15- 4:00 p.m.	Dressing, Grooming, Hygiene and Homemaking/Leisure Time	Respite Director
4:00- 5:00 p.m.	Alternative Communication (sign language, etc.)	Special Education Teacher

Sunday

Time	Topic	Resource Person
1:00- 2:20 p.m.	Health, Medication, Medical Information/ Nutrition and Feeding	Registered Nurse
2:20- 2:35 p.m.	Break	
2:35- 3:30 p.m.	Physical Management (e.g. lifting, moving, transferring)	Hospital Physical Therapy Director
3:30- 4:00 p.m.	Respite Care Policies/Procedures	Respite Director

WHAT SHOULD YOU LOOK FOR IN A PROVIDER?

The training we've been talking about is important, but it isn't everything. The right kinds of information and skills can only work in the right hands (and heads).

So what do you look for in a respite provider?

There is no profile of a perfect (or even preferred) provider. Families seem to differ in the kinds of people (age and other characteristics) that they prefer. But while there isn't a consensus of opinion, there certainly are some useful comments from parents and others.

One parent had this to say:

". . .I think that professional kinds of people are excellent, but I think the most important criterion is compassion. . .that it's more than just a job. They have to have a feeling and an understanding for these kinds of kids. They have to see something beyond a handicap and a job. . .We have mothers and grandmothers; we have young people and older people - kind of a wide range of people who are doing respite. Some obviously need the work, but most have a real interest in the kind of work they're doing."

Other parents put responsibility at the top of their list:

". . .There is a maturity about our respite workers. They're willing to take on responsibility. They're not afraid to make a decision if a decision has to be made."

While it may prove helpful, it doesn't seem to be necessary for providers to have previous experience working with disabled people. According to one respite director:

"We have two former special education teachers and one young secretary with no experience working with handicapped kids. She's one of the very favorite workers."

More than one program director said that experience working with kids (disabled or non-disabled) is good preparation for respite. They added that providers need to realize respite is care: sometimes people's expectations of the job can be unrealistic and they become disillusioned with the work.

As far as age is concerned, conversations with families show that some definitely prefer an older person as a provider. There is an obvious maturity and a sense of child care experience about a grandmother, for example. And that can make people more comfortable about leaving their child in someone else's care, especially at first.

You may find, in fact, that retired individuals may be excellent candidates for respite providers. Since the work is part-time, it could serve to supplement social security and other retirement benefits.

Other parents prefer a younger pro-

vider - someone to play more actively with older children, for example. Sometimes the lifting required in a respite situation can be handled better by a younger person. How young is a good question. One program used high school students as providers when if first started out. Apparently, some parents were not comfortable with that option. As one member of the program's steering committee put it, "Parents seemed to feel much more comfortable with respite after the program stopped using very young people." That is not to say, of course, that certain high school age people couldn't work out very well in some capacity with a respite program. One parent recalled this experience with her fourteen-year-old daughter who is handicapped:

"I called (the respite program) because I was taking a class, and I really needed to get some time in on a paper. . .stuff I just couldn't do with Erin. Larry was out of town, so he wasn't home to do something with her. So I called and asked if Erin could come over to the center on Friday after school and stay until Saturday afternoon. They said sure, and a couple of days later (the director) called and said Amy, who is almost exactly Erin's age and volunteers (at the center) was thinking it might be fun for her and Erin to either go swimming or go downtown - or something. But they thought they'd take the bus and go in for lunch on that day - that it would just be kind of special. Now

Where to advertise for respite providers?

Laundromats

Health clinics

Community centers

Stores

University/college campuses

Military bases

Retired Teachers Association - other community groups

TV and radio stations

Newspapers

Job Service - good for initial screening

Larry and Joan Carroll, Juneau, AK, have been active in the St. Jude respite care program. The Carrolls use respite care for their daughter Erin.

these are the things that endear the respite center to us."

Whether families prefer female or male providers is again a matter of individual preference. Some families may feel strongly that one or another is more appropriate for their child or other family member. In one community, for example, a respite director was looking for male providers to help families who have adult handicapped sons. The providers could then serve as occasional companions, taking the sons to the movies, ballgame or other activities. What the preference will be among families in your community should be one of the items for discussion when parents and others decide what kind of care they want.

It's also important that families and providers alike are aware of some of the realities of respite care - at least some of the things that have happened elsewhere. For starters, in some communities it can be difficult to find providers or, more specifically, providers whose schedules match families' needs for respite. Sometimes it can be difficult to keep the same providers for an extended period, since they may need to earn more money than they're making in the respite program. That can lead to frequent changes in providers which can be disheartening to families who get accustomed to certain individuals.

A suggestion would be to let prospective providers know as specifically as you can, how much they might expect to earn. Since most respite programs seem to start out slowly and then take off once the word gets out, you'll want to let providers know about that trend. You'll probably do best to caution people that, in most instances, respite is part-time, and they need to look at their budgets accordingly before they choose to become providers.

As with most cooperative ventures, a mutual respect and trust between family and provider is essential. To help foster that, according to parents, families shouldn't be timid. They should tell workers what they want in the way of child and family care.

On the other side, providers should be able to expect responsible treatment from families. One respite worker stressed the importance of parents updating information on their child when the worker arrives. As she put it, "Things change and parents can overlook those details." Parents should be on time in returning home or in picking their children up from a respite center. They should also be fair in terms of what they expect from the provider. Their job is to provide responsible care for a family member or members. And while some providers may choose to pitch in on a household chore if they've got time, they are not there to do the family's dishes, laundry, or to clean house. Nor are they expected to run full-scale educational programs for family members.

Providers are there, however, to keep the family member(s) occupied in appropriate activities. Most families seem to agree that that does not mean just "plugging them in" in front of the TV (although

at times TV can be appropriate too, depending on the person and the circumstances). One program director said that she encourages respite providers to take the family member out into the community for activities when it's agreeable with the family. As with all aspects of respite, parents and other family members will be able to offer good advice on what are appropriate and enjoyable activities for the person involved.

FOR PROVIDERS AND OTHERS: AN IMPORTANT NOTE ON LIABILITY

Although some respite care programs have malpractice and liability insurance to protect them in the event of an accident or other mishap, a number of programs do not, primarily because of cost restrictions. Rather, it is not uncommon for programs to use waiver of liability and other consent forms, signed by parents or guardians in good faith, to release providers and programs from liabilities. A few examples of those kinds of forms (currently used by respite programs in the state) follow on the next pages.

Keep in mind, however, that these forms are not guarantees against legal problems. The best advice is to get legal counsel to assist you in making sure that you, your organization, respite program and providers are protected adequately. That may depend in large part on what kind of program you decide to have. So, again, please use these samples as just that.

The forms included are:

Waiver of Liability (p. 57)

Agreement for Emergency Medical Care (p. 59)

Medical Care and Hospital Authorization (p. 61)

Medical Information Consent Form (p. 62)

Permission to Transport (p. 63)

Sample Form

WAIVER OF LIABILITY AGREEMENT

I (We) agree that the _____
(Name of respite program)

will not be held responsible or liable in any way whatsoever as a result of any incident which might be construed to adversely affect the health, safety or welfare of my (our) child (or other person in our care) while that person is in the care of a respite care provider supplied to us through the _____.
(Name of respite program)

I (We) knowingly waive all my (our) rights to hold the _____
(Name of respite program)

and the respite provider liable as a result of any incident which might be construed to adversely affect the health, safety or welfare of my (our) child (or other person in our care). I (We) make this agreement and waiver in consideration of the service being provided us by the respite program named above.

I (We) have fully disclosed to the _____
(Name of respite program)

information about our child's medical condition, needs and functions (or those of another person in our care), and acknowledge full responsibility for any failure to disclose that information.

*Please use form as sample only.
Legal consultation is advised.

Sample Form

WAIVER OF LIABILITY AGREEMENT
(continued)

I (We) have read this agreement and voluntarily and knowingly agree to the terms contained herein.

Date: _____ _____
(Expires_____) Signature of parent/guardian

_____
Signature of parent/guardian

I,_____of the
(Name of respite provider or director)

_____ ,have observed
(Name of respite program)

the parent(s) or guardian(s) whose signatures appear above, reading this agreement and have, to the best of my ability, answered any questions or made any explanations requested by them.

Date: _____ _____
(Expires_____) Signature of respite provider or director

*Please use form as sample only.
Legal consultation is advised.

Sample Form

AGREEMENT FOR EMERGENCY MEDICAL CARE

I (We) hereby agree that _____, or any other
(Provider's name)

_____respite care provider for our child (or other person in our
(Respite program name)

care), is given permission to request or approve any medical attention needed by my (our) child (or other person in our care).

The respite care provider will not be held responsible or liable in any way as a result of seeking medical attention for our child (or other person in our care) in the event of an emergency and if we are unable to be contacted. We further agree that the respite care provider will not be held responsible or liable in any way for administering medications according to our written instructions as provided below:

_____

_____

_____

_____

_____

_____

I (We) further agree to assume full financial responsibility for any medical or health care given our child (or other person in our care) while under the care of a_____
(Program name)

respite care provider.

Date: _____ _____
(Expires_____) Signature of Parent/Guardian

_____
Signature of Parent/Guardian

*Please use form as sample only.
Legal consultation is advised.

Sample Form

AGREEMENT FOR EMERGENCY MEDICAL CARE
(continued)

I,_____of the
(Provider's name)

_____respite care program, have observed the parent(s) or guardian(s)
(Program name)

whose signature(s) appear on this agreement document, reading this agreement and have, to the best of my ability, answered any questions or made any explanation requested by them.

Date: _____ _____
(Expires_____) Signature of respite provider or director

*Please use form as sample only.
Legal consultation is advised.

Sample Form

MEDICAL CARE AND HOSPITAL AUTHORIZATION

I (We) consent to such necessary treatment by Dr. _____ _____ ,
(Name of doctor)

his assistants or his designees as is necessary in his judgement for,

_____ .
(Name of person receiving respite care)

This authorization shall remain effective until _____ ,
(date)

unless sooner revoked in writing delivered to said agent(s).

Date: _____ _____ _____
(Expires _____) Signature of Parent/Guardian

_____
Signature of Parent/Guardian

_____
Witness:
Respite care program
provider or director

*Please use form as sample only. Legal consultation is advised.

Note that this form should be on file with the physician and hospital or clinic, as well as with the respite program.

Sample Form

MEDICAL INFORMATION CONSENT FORM

I (We) recognize that it is important for respite providers to have sufficient information about the persons they are caring for. Therefore, I (We) consent to the release of any and all of the medical and care information supplied by me (us) to the _____
(Name of respite program)

to the respite provider caring for our child (or other person in our care). Likewise we consent to the release of the above information to any other individual who works for the respite program named above who would need access to that information.

I (We) further agree to the release of that information to any medical or other emergency personnel as necessary.

My (Our) consent to the release of the medical and care information as described above is given provided our child (or other person in our care) is not identified for use in academic studies, statistical computations, research analyses, or for any other scientific or educational purpose.

I (We) agree not to hold the _____
(Name of program)

respite care program and its respite providers liable for the release of said information.

Date: _____ _____ _____
(Expires_____) Signature of parent/guardian

_____
Signature of parent/guardian

_____
Witness:
Respite care program
provider or director

*Please use form as sample only.
Legal consultation is advised.

Sample Form

PERMISSION TO TRANSPORT

I (We), the parent(s)/guardian(s) of _____, give our permission
(Name of person receiving care)

for _____, a respite care provider,
(Provider's name)

to transport our child (or other person in our care) to:

_____
(Description of event and location)

on this _____ of _____, 19 _____ .
(day) (month) (year)

I (We) understand that such transportation is restricted to the _____.
(Geographical areas)

I (We) have checked and confirmed that the vehicle to be used for transportation is currently insured in such a manner as to provide adequate coverage for the driver and passengers of the vehicle.

Date: _____ _____
Signature of parent or guardian

_____
Signature of parent or guardian

*Please use form as sample only.
Legal consultation is advised.

Ludy Jacobs, Anchorage, AK, and her son Jason. Ludy has been active in respite programs and other family support efforts.

SOME OTHER CONSIDERATIONS: WHO'S GOING TO FOOT THE BILL?

If you decide you want a respite program in your community, an obvious question is who's going to pay for it?

To date, the respite care programs in Alaska have been funded primarily by the state's Department of Health and Social Services, Division of Public Health and Division of Mental Health and Developmental Disabilities. In most cases, the organizations sponsoring the programs on the local level have used those funds to provide respite care at no cost to eligible families. The reasoning, in large part, has been that families with disabled children or adult members already have significant expenses related to that disability, and in many cases, could not afford to pay for respite. Consequently, many people have considered free care the best kind of support. Whether, in fact, it is should probably be one of the questions on your list as you figure out how to fund respite care in your community. To help you answer that question and some others, we'll take a look at what's held true in some communities.

As we noted earlier, a respite program often starts out slowly and then, as more families begin to use it and use it more often, the program can really take off. One parent who's active in a respite program had this advice: "Tell people not to be discouraged if it's not being used right away. Pretty soon you won't have enough hours." It's not unusual, for example, for the number of families using a program to double or even triple in six months to a year.

The number of hours of respite that can be provided in a community is limited in large part by the funds available - in short, by the amount you've got to pay providers and cover other program costs if there are any. As more than one community has found out, grant funds can fall short of filling the bill. In one community, for example, the growth of the respite program has meant that families are now severely limited in the number of hours of care they can have each month - far fewer hours than they had become accustomed to. For some families, that has been a very frustrating experience. They're back at the (usually unsuccessful) task of trying to find other child care options - the reason for using respite in the first place. In another community, the respite program ran out of subsidized hours completely with two months left in a quarter.

What do these examples really have to say to you - to a new respite program? First of all, they point out the need to estimate carefully the amount of respite care that is likely to be needed for a year's period. How many families will be using the program, for example; how many hours of care per family? That kind of information will be essential for determining a budget and if applicable, applying for funds, whether from the state or from private sources (businesses, corporations, foundations, for example). In addition to using your knowledge of the community, you may want to contact other respite programs for help in putting that

information together. A caution: You'll want to be careful not to overestimate the need for respite, especially in the beginning when things may go slowly. Should you have monies left over in a given period, funding sources may feel that the need for the service really isn't there.

We've seen that grant funds may be too limited to meet the actual demand for respite in a community. And grant funds certainly may become more limited; there are no guarantees about government monies for human service programs. In light of that reality, respite programs will do well to build in some means of self-support. Which brings us back to the subject of charging families for care. While, as we've already pointed out, many programs do not charge, and, legitimately, there are families who cannot afford respite, there are also families who can afford to pay at least part of the cost. Charging them a reasonable amount could help prevent cutbacks in care that could easily become necessary. In fact, if grant funds are your only source of program support, families should probably be prepared to settle for fewer hours of care down the road. The better alternative may well be to start out charging a reasonable fee and avoid the frustration later.

There are some other reasons why charging for respite may be something you'll want to consider. State funds from the Division of Mental Health and Developmental Disabilities, for example, can only be used to provide care for persons whose handicaps meet the state's current definition of developmental disabilities. That definition includes disabilities which are attributable to mental retardation, cerebral palsy, epilepsy, or autism; or any other conditions found to be closely related to mental retardation because of a condition which results in impairment of general intellectual functioning or adaptive behavior similar to impairment resulting from mental retardation. Changes in the state's definition have been proposed which would include a larger number and variety of handicaps and impairments.

However, with only a couple of exceptions at present, state funds cannot be used to provide respite care for a person whose disability is a physical or emotional rather than mental impairment. If you feel that a need in your community is care for children and/or adults who are physically disabled, you'll probably have to find other sources of support for that respite. **(One program in the state provides care to persons with physical disabilities, but those families must pay 100% of the cost of care; the state subsidy is used only for persons whose conditions meet the definition above.)**

There are some other considerations, more philosophical than financial, for thinking about charging families who can afford to pay for respite. As we said in the introduction of this book, family support programs should take after the usual kinds of child and family care. When people look to babysitters, day care centers, and other kinds of care, they usually expect to pay for those services. In exchange they want to be in the position

of saying what kind of care is needed, and when and where it's provided. We don't want respite and other kinds of support to separate the families who are using them from the mainstream - the purpose is to help keep them in it. Giving families the opportunity to be in control of the supports they use, including at least part of the responsibility for paying for them, may be most in keeping with that philosophy.

POSSIBILITIES FOR RESPITE THROUGH OTHER PROGRAMS

In addition to the options we've already looked at, there's also the possibility of providing some families with a 'respite' through other, already established, support programs. Depending on the program - its location, who it's serving and other circumstances - existing programs can have the added benefit of being familiar to (and trusted by) people in communities.

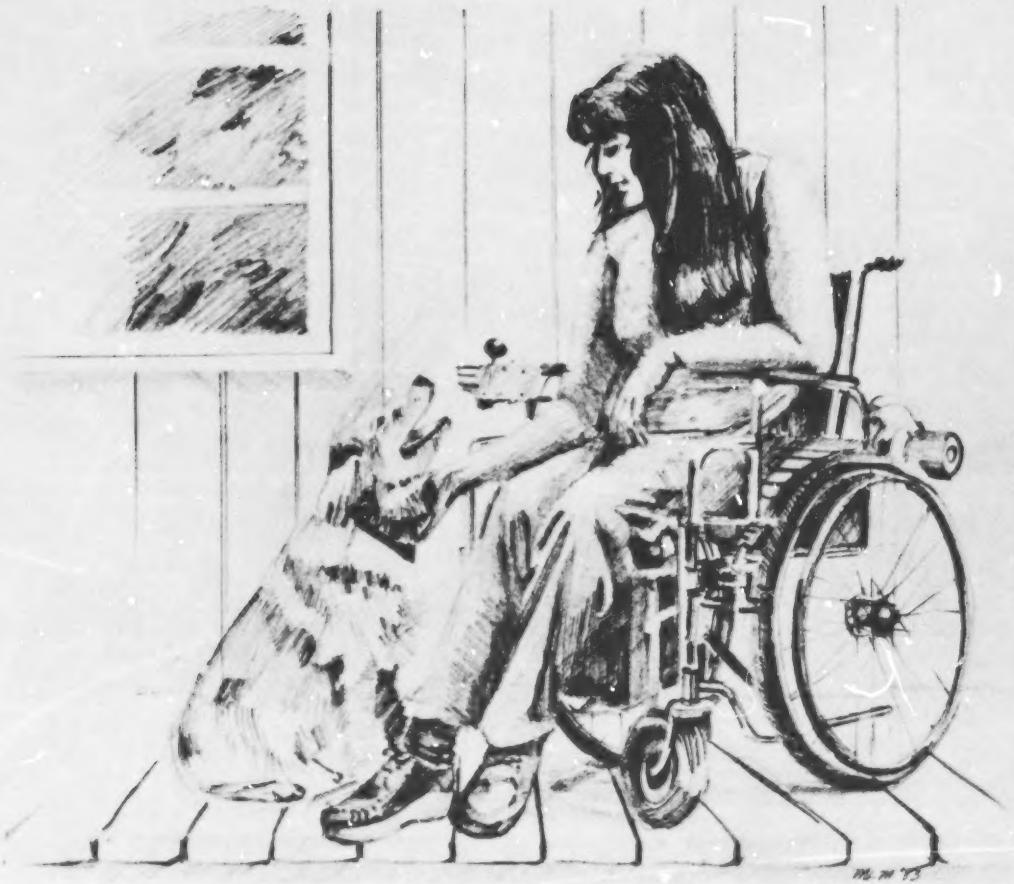
For example:

The state is providing in-home support services through the Home Health Aide and Homemaker Services programs to families with ill or disabled family members. Like respite care, these programs are also intended to help keep families together and individuals out of institutions.

For more than ten years, the Homemaker Services program has provided trained people to go into families' homes,

"The river is the highway for our people. All his life my grandfather has lived on that highway and gone back and forth on it to hunt and to visit. Since he has had a stroke he can't be active any more, but he can see the river from his house. And people come and go and greet him on their way to and from the river. He can still know about the things that matter to him and be a part of life. So far, my grandmother and other relatives have been able to take care of him. But I'm afraid to think what would happen if something happens to her."

Donna Christie
Galena, Alaska



Support for families also is provided through the state's Home Health Aide and Homemaker Services programs. Glenda Moore, Fairbanks, AK, is one of the participants in the Home Health Aide program.

both in urban areas and villages, and assist with household chores, shopping, hauling water, chopping wood, meal planning, personal hygiene, and so on. But there can be more.

The emotional support the program can provide is also important, not only for the individual who may be ill or disabled, but for the whole family. While the program can't be used solely for respite care, the homemaker's presence can give other family members a chance for an occasional break from the responsibilities of caring for someone else.

A newer service, the Home Health Aide program provides health-related personal care to family members who are ill or disabled. A trained person comes into the home to help with such things as toileting, dressings, exercising, the use of adaptive equipment and so on. This program, which is expanding to serve more outlying areas, can also give family members a break.

Let's say, for example, that an older couple in a community could use some support. The woman is bedridden and her husband, who's in relative good health, is the only person available to take care of her. It is, for him, nearly a round-the-clock responsibility. He does leave the house for shopping and other errands, but he's usually rushed. There isn't a chance for a real break, for him to do something he might enjoy away from the house. The Home Health Aide program might, for example, be just the right kind of support for this family - medically and emotionally. While the woman is receiving the attention of a health professional, her husband can have some time for himself.

In addition, the state also sponsors skilled nursing and related services to people in their homes. Through this program, a professional nurse is available to administer medications, injections, to provide care following surgery, as well as care for terminally ill patients.

Other possibilities for temporary care include use of foster care, or even group homes or children's facilities. The Division of Family and Youth Services, as part of their family support services and protective services, can help arrange care through one of their licensed foster homes. While not generally used for 'respite' care, short-term and occasional foster home care can be a major source of help to families, and keep people in a family setting close to home during times of high emotional stress or other special needs. Children's facilities, such as Barrow Receiving Home, Hospitality House in Fairbanks, Alaska Children's Services in Anchorage, the Juneau Children's Home or Bethel Receiving Home, or facilities licensed for short-term care, provide residential services to children and may be utilized from time to time for short-term or respite care. These agencies are supported in part by funds from the Division of Family and Youth Services. You can work out special care arrangements through voluntary placement agreements with the Division of Family and Youth Services staff.

The residential services organizations which serve handicapped and develop-

mentally disabled children and adults may also provide respite care in an emergency or by special arrangement if other support services are not able to be obtained locally. Hope Cottages in Anchorage, Fairbanks Rehabilitation Association, REACH or CHILD in Juneau, are examples of agencies that offer residential services. Short-term care in one of these agencies' programs can sometimes make the difference in preventing long-term out-of-home placement or institutionalization.

While some people in the past might have felt guilty about using this type of care for their son, daughter, or relative, there is now greater understanding and support for these types of temporary care.

These programs serve to remind us that 'respite' support does not necessarily have to be a separate service. Rather, respite can be an indirect benefit of a program or an effort that's already underway in a community. The examples on the previous pages can be food for thought for your own ideas. (See the listing of resources at the back of this book for more information.)

"BUT WHAT IF WE DON'T NEED (OR WANT) AN ACTUAL 'PROGRAM'?"

The kind of full-fledged programs we've described in previous sections aren't, of course, the only ways to provide support to families. Maybe in your community the number of families needing short-term care is small and likely to stay that way for the time being. Maybe a structured program is more than you think you need or want - at least for now. And yet there are families who need support.

One suggestion might be for those families to get together over a cup of coffee to talk about what their needs are and to figure out the simplest ways to meet them.

If there are severely handicapped family members who need to be cared for, it might be possible for the families involved to put together a training session for a few individuals in the community who would be interested in part-time work providing that care. The training session could be done along the lines of the example we presented earlier (pages 50-51), tailored to the particular needs of the families in your community. For example, if none of the handicapped family members uses sign language, that could be eliminated from the training. If, on the other hand, there are a number of physical disabilities involved, you may want to place more emphasis on proper lifting and transfer techniques. It'll depend on the families.

Just how such a training session would be organized and sponsored will depend a lot on the resources available in the community. In all likelihood, a school nurse or public health nurse, village health aide, special education teacher, infant learning teacher, parents and other family members would be willing to donate a reasonable amount of time to help give the training. A commitment of two to three hours would seem to be reasonable, particularly if what the

volunteers are going to cover can be worked out clearly ahead of time. At a minimum, an understanding of the handicapping conditions involved (e.g. Are there medical requirements, special diets, or unusual behaviors to be aware of?), as well as emergency first aid practices would seem to be essential for the people who would be taking care of severely disabled individuals. Beyond that, parents and other family members could offer valuable firsthand knowledge about the person in the family who needs the care.

This kind of training session could be held at your school, a church, community hall, a library, a community college. It could even be offered as a course for credit, as has been done in a couple of instances with community colleges. Whether that option would work for you would depend on whether you think people in the community would be willing to pay a fee for the training - usually the case with a college course of that kind. Another option might be to offer the training as an adult education course through your high school.

Regardless of who actually sponsors the training or where it's held, the important thing is that people in the community get the training they need to provide family support. A list of those people who have been trained can then be given to families. The families, in turn, can contact those providers directly - just as they might for other kinds of child (or adult) care.

Since this kind of in-home support is not a structured program with an adminis-

"It was hard at first to trust anyone else with our daughter, but we've all learned from her involvement in the respite program. She's making some real choices now about when she wants to be with us and when she wants to be more on her own."

Parent of a handicapped child

trator and the kinds of record-keeping and coordination required by state grant guidelines, state funding would probably not be an option. Rather, the families would have to cover the costs of the service - i.e. pay the care providers for their time. As long as that fee is kept to a reasonable level, many families should be able to afford it. (What's 'reasonable' in your community would have to be negotiated among the families and care providers. **One Hint:** There may be people in the community looking to add to their existing incomes. Retired persons, for example, who can earn only a certain amount over their social security might be good candidates.)

There may, however, be some families who can't afford to pay for care, especially if they need it on an extended basis. And there may be families who can't afford to pay for care at all. These are the kinds of problems those of you close to the community will be aware of. Likewise, you may be aware of some solutions. Maybe there's a service club or a church group in the community that would help pay for care when a family cannot. There may even be people willing to volunteer occasionally.

AND, IF IT AIN'T BROKE, DON'T FIX IT. . .

It's important to keep in mind that respite care and other kinds of family support services aren't for everyone.

Some families don't need them; their informal networks of family and friends are providing the support they need. Other families may just not be interested; they may prefer to keep family matters to themselves.

In other cases, people may just want time to see how respite or another service is going to work before they try it. Whatever the situation, respect for the family's decision - and recognition that the family system is doing fine without outside help - is essential. The support service isn't intended to replace something that's working. It's for those times when families need something extra.

THE IMPORTANCE OF GETTING THE WORD OUT

Making the public aware of your family support services is something you don't want to overlook. You'll want to get the message out not only to families who might be interested in using the service, but also to the community in general. You can use their support along the way - as volunteers, fundraisers, potential care providers, and so on.

Word-of-mouth seems to be an effective way of spreading the message to families who need the services - at least in smaller communities. In addition, some programs have prepared brochures, and at least one parent group is talking about a complete service-information packet for parents of handicapped children who are new to the community.

Other ways of reaching families and the general public include posters, letters sent to doctors, dentists, schools, military bases, churches - wherever you think the

Respite

Trained caretakers give break to families of handicapped

By RANDI SULKIN
Daily News Staff Writer

They learned about food groups, maneuvering a wheelchair, taking temperatures, creative playtime, sign language and hygiene. And that was just the beginning.

It makes good sense for anyone to learn about nutrition, prevention of household emergencies and basic health. But for families of people with severe disabilities, employing a respite care provider with these skills enables them to take a vacation, attend a meeting and add other dimensions to their lives.

Last weekend the Ketchikan Association of Parents for People with Special Needs (KAPPS) presented a program to train new respite care providers who are employed by the families who need them. The family pays one-fourth of the cost, which the State of Alaska supplements with funds from the Division of Developmental Disabilities.

Eight families in Ketchikan have requested respite care. Before last weekend's training, Ketchikan had two providers; now there are 13.

Respite care is specialized, short-term temporary care of a developmentally disabled child or adult, KAPPS guidelines say. The program was designed to relieve families from the burden and stress of round-the-clock care while creating one more avenue to prevent institutionalization.

"Severely handicapped people have a right to stay in their own homes, with their own families, in their own communities, rather than being institutionalized," said Joanna De Santo, respite care coordinator. "But that is only possible if adequate support systems are available. Respite care is one of those support systems. It replicates what's normal in most other families." A person with developmental disabilities often requires 24-hour supervision. Respite care offers a break from that supervision, just like a baby-sitter provides a break for families of persons without special needs.

The idea behind respite care is not to change the family routine, but to continue it, Ms. De Santo said. And because families choose their own respite care workers, they are able to build a solid rapport with the person continuing that care.

The program also allows family members to meet some of their own needs and reduce the stress caused by constant care, Ms. De Santo said. Having that time off can make a crucial difference in the family's lives.

Just ask Barbara and John Joyner of Ketchikan, who have come to rely on respite care for their 7-year-old son Joshua.

Because of a respite care program in Anchorage, John Joyner was able to attend school and have Joshua with him while his wife continued working in Ketchikan. Because of respite care in Ketchikan, the Joyners were able to spend three weeks on vacation in California together, while previously they always had to take vacations separately.

"It was exciting to discover ourselves again, to have a refresher and some time to relax and enjoy," Ms. Joyner said. "And it was important for Joshua (that we) not to upset the home routine."

Joshua needs constant watching and doesn't know how to do things for himself, Ms. Joyner explained. He sometimes has seizures and needs medication and someone always there "to watch him and love him," she said.

"Respite care workers have been trained to understand. Half the battle is finding someone to care," she said. "Then you can feel at ease. You know they're responsible. For some parents it might be difficult to accept, but you need to be able to say it's all right. You have to be able to trust somebody."

Respite care can be a growing experience for the child as well as the parents, Ms. Joyner noted. Joshua is learning more social skills and ways to "come out of his own world."

"Without a family around, it's hard. The little breaks make a big difference."

The program in Ketchikan will continue to grow with additional state funding next January if the community can prove it wants and needs the program, Ms. De Santo said.

"The state will only put money where consumers want it," she said. "A program like this always has a slow start, but it really flies when parents use it and they feel the benefits. Then they tell other families and they build trust in the program."

Newspaper articles like this one done by the Ketchikan Daily News can help people throughout the community better understand the special needs of some families.

"Without relief like this we would have given up and our son would probably live in an institution. What would that cost compared to the $200 a month the respite care costs?"

Parent of a handicapped child

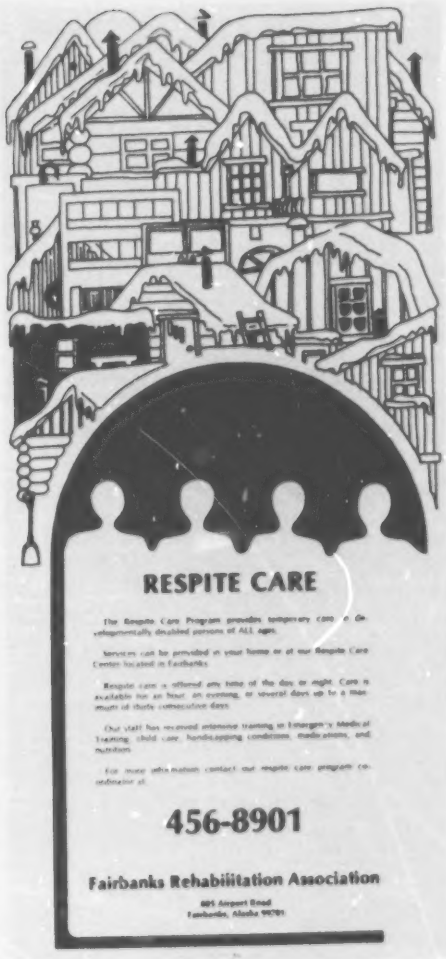
word might do some good. There are also newspaper articles and appearances on local TV and radio talk shows. Those stations will often be willing to give some time to a good cause: give a call to the station manager and explain the message you want to get out. Those kinds of public appearances can also help to counter some of the resistance you may find in the community. Don't be surprised, for example, if there's some resentment about the respite service (especially if state funds are involved). Some people in the community may feel it's nothing more than "free (or cheap) babysitting" and "Why can't I get that for my (normal) kid too?" (One parent said a co-worker expressed that sentiment to her about respite care. It took some time and talking to ease the situation over.) The more you can explain why respite is important to families, the greater the chance for understanding.

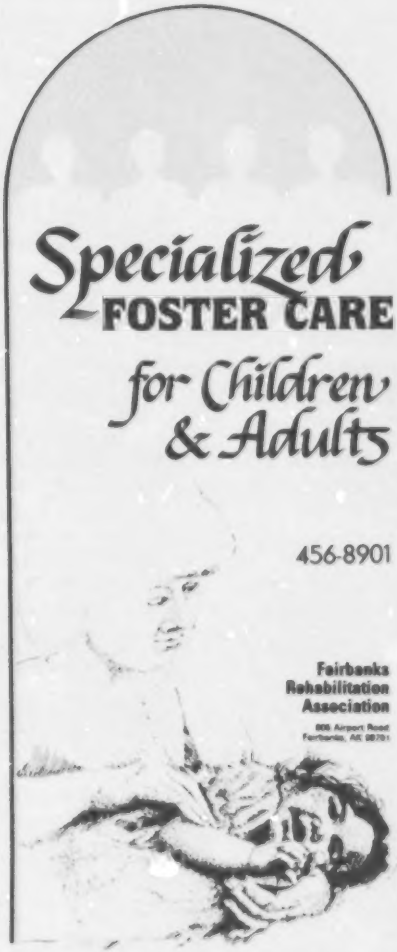
Another parent had a useful suggestion: get different segments of the community behind you. In addition to parents and consumers, ask a representative of the business community, the media, and the school system to be on your advisory group or board. If that's not appropriate, invite them to an informational 'open house' to introduce yourselves and what you're doing. You might use that opportunity to inform people in the community about the special needs of families with handicapped persons and why programs like respite can make the difference.

BEST COPY AVAILABLE

SITKA-PACS, inc.
RESPITE CARE - What is it?
Respite care is temporary care for families of handicapped individuals of any age
Who can receive it?
Apply family who has a child or an adult with needed aid to severe physical and/or mental handicaps.
SITKA-PACS, inc.

Brochures or other hand-outs describing family services can be helpful. Above is an illustration of one prepared by Sitka-PACS, Inc.





Posters can be very useful for getting the word out in the community. They can be placed in stores, clinics, doctors' offices, schools—wherever families will see them. The posters on this page were done for Fairbanks Rehabilitation Association programs.

BEST COPY AVAILABLE

FOR ASSISTANCE AND MORE INFORMATION

RESPITE CARE PROGRAMS

Catholic Social Services
811 W. 6th Avenue
Anchorage, AK 99508
277-2554

Central Peninsula Mental Health Center
P.O. Box 4683
Kenai, AK 99611
283-7501

Fairbanks Rehabilitation Association
805 Airport Road
Fairbanks, AK 99701
456-8901

KAPPS (Ketchikan Association of Parents for People with Special Needs)
P.O. Box 6280
Ketchikan, AK 99901
225-2914

Kodiak Aleutian Mental Health Center
P.O. Box 712
Kodiak, AK 99615
486-5742

PACS (Sitka Parents Association for Children with Special Needs)
P.O. Box 4512
Mt. Edgecumbe, AK 99835
747-8733

St. Jude Center
Route 3, Box 3050
3272 Hospital Drive
Juneau, AK 99801
586-2624

Alaska Division of Mental Health and Developmental Disabilities
Pouch H-04
Juneau, AK 99811
465-3370

DAY CARE, FOSTER CARE, RESIDENTIAL AND RELATED FAMILY SERVICES

1. Alaska Division of Family and Youth Services
Pouch H-05
Juneau, AK 99811
465-3170

Local phone numbers:

Northern Region, Fairbanks	452-1844
Barrow	852-5600
Delta	895-4452
Fairbanks	452-1844
Fort Yukon	662-2331
Galena	656-1667
Nenana	P.O. Box 359, Coghill Bldg., Nenana, AK 99760
Northwestern Region, Nome	443-5247
Kotzebue	442-3226
Nome	443-5247
Unalakleet	624-3371
Southcentral Region, Anchorage	561-4240
Anchorage	276-1450
	274-1615
Cordova	424-7133
Dillingham	842-5237
Eagle River	694-9546
Glennallen/Copper Center	822-3089
Homer	235-7114
Iliamna	235-7114
Kenai	283-3136
Kodiak	486-6173
McGrath	524-3848
Seward	224-5236
Wasilla	376-2486
Unalaska	581-1236
Valdez	835-4789
Southeast Region, Juneau	586-1861
Ketchikan	225-9639
Petersburg	772-3877
Sitka	747-8608
Western Region, Bethel	543-3141
Aniak	675-4377
Alakanuk	238-3416
Grayling	461-8001
Kwigillingok	769-8001
Mountain Village	591-2613
Scammon Bay	422-8001

2. Alaska Division of Mental Health and Developmental Disabilities
Pouch H-04
Juneau, AK 99811
465-3370

Statewide Client Program Manager
3601 "C" Street
Anchorage, AK 99502
561-4247

Harborview Developmental Center
Box 487
Valdez, AK 99686
835-4344

3. Alaska Division of Local Government Assistance/Day Care Assistance Programs
225 Cordova St.
Building B
Anchorage, AK 99501
264-2211

Local phone numbers:

Anchorage	264-6700
Aniak	675-4476
Bethel	543-2840
Cordova	424-3680
Craig	826-3228
Delta Junction	895-4656
Fairbanks	452-1011
Ft. Greely	873-3284
Glennallen	822-3485
Haines	766-2486
Homer	235-7035
Juneau	586-3300
Soldotna	262-9378
Ketchikan	225-6151
Kenai	262-9378
Kodiak	486-6396
Kotzebue	442-3157
McGrath	524-3363
Metlakatla	886-4441
Nome	443-2130
Noorvik	636-2102
North Kenai	262-9378
Petersburg	772-3227
Seward	224-3027
Sitka	747-5633
Valdez	835-4951
Wasilla	376-5227
	376-4080
Wrangell	874-3430

4. Children's Receiving Homes

Presbyterian Hospitality House
1401 Kellum Street
Fairbanks, AK 99701
456-6445

North Slope Borough
Children's Receiving Home
Box 371
Barrow, AK 99723
852-7007

Bethel Receiving Home
Box 271
Bethel, AK 99559
543-2068

Alaska Children's Services
1200 East 27th
Anchorage, AK 99504
276-4515

Alaska Youth Village
(Juneau Children's Home)
Box 370
Juneau, AK 99802
789-2126

5. Private Non-Profit Organizations

Access Alaska
941 E. Dowling Road
Anchorage, AK 99502
272-5494

Bethel Social Services, Inc.
Box 271
Bethel, AK 99559
543-2840

CHILD, Inc.
9177 James Boulevard
Juneau, AK 99801
789-7479

Fairbanks Rehabilitation Association
805 Airport Road
Fairbanks, AK 99701
456-8901

Gateway Opportunity Center, Inc.
P.O. Box 7262
Ketchikan, AK 99901
225-9641

Hope Cottages, Inc.
2805 Bering Street
Anchorage, AK 99504
278-9641

P.A.D.D., Inc. (Protection and Advocacy for the Developmentally Disabled)
325 East 3rd, 2nd Floor
Anchorage, AK 99501
274-3658
Fairbanks - 456-5401
Juneau - 586-9865

REACH, Inc.
P.O. Box 1266
Juneau, AK 99802
586-2360

St. Jude Center
3272 Hospital Drive
Juneau, AK 99811
586-2624

Satellite Home Program/Alaska Resources for the Moderately/Severely Impaired
3401 East 42nd Avenue
Anchorage, AK 99504
561-1133

6. Homemaker Programs

Alaska Management Technologies
369 S. Franklin, Suite 101
Juneau, AK 99801
586-3944

Homemaker Program
3401 E. 42nd Avenue
Anchorage, AK 99504
562-2922

Homemaker Program
P.O. Box 310
Bethel, AK 99559
543-2144

Homemaker Program
528 5th Avenue, Room 211
Fairbanks, AK 99701
456-6208

Homemaker Program
106 Main Street Upper
Ketchikan, AK 99901
225-5810

Homemaker Program
P.O. Box 149
Nome, AK 99762
443-2772

Homemaker Program
P.O. Box 2048
Palmer, AK 99645
745-2900

HOME HEALTH SERVICES, PUBLIC HEALTH NURSING SERVICES

1. Alaska Division of Public Health
Section of Nursing
Pouch H-06E
Juneau, AK 99811
465-3150

Local phone numbers:

Bethel Regional Office	543-2110
Northern Regional Office, Fairbanks	452-1593
Fairbanks Health Center	452-1776
Griest Family Services Center	852-5600
Nome Health Center	443-5229
Tok Health Center	883-4104
Unalakleet Health Center	624-3255
Southcentral Regional Office, Anchorage	561-4215
Dillingham Health Center	842-5981
Homer Health Center	325-8857
Kenai Health Center	283-4871
Kodiak Health Center	486-3319
McGrath Health Center	524-3868
Naknek Health Center	246-4250
Palmer Health Center	745-4258
Seward Health Center	224-5567
Valdez Health Center	835-4612
Wasilla Health Center	376-2437
Southeastern Regional Office, Juneau	586-1120
Craig Health Center	826-3433
Haines Health Center	766-2125
Juneau Health Center	586-3736
Ketchikan Health Center	225-4350
Petersburg Health Center	772-4622
Sitka Health Center	747-3255
Wrangell Health Center	874-3615

2 Home Health Aide Programs

Fairbanks Home Health Care
1512 Cushman Street, Suite 202
Fairbanks, AK 99701
452-6404

Homemaker Program
P.O. Box 2048
Palmer, AK 99645
745-2900

Ketchikan Home Health Care
1734 Tongass Upper
Ketchikan, AK 99901
225-5180

3. Regional Health Corporations

Aleutian-Pribilof Islands Association, Inc.
1689 "C" Street/Second Floor
Anchorage, AK 99501
276-2700

Bristol Bay Area Health Corp.
P.O. Box 10235
Dillingham, AK 99576
842-5266

Cook Inlet Native Association
670 W. Fireweed Lane
Anchorage, AK 99503
278-4641

Copper River Health Department
Drawer H
Copper Center, AK 99573
822-5241

Kodiak Area Native Association
P.O. Box 172
Kodiak, AK 99615
486-5726

Maniilaq Association
P.O. Box 256
Kotzebue, AK 99752
442-3311 or 3312

North Slope Borough Health & Social Services Agency
P.O. Box 69
Barrow, AK 99723
852-3999

Norton Sound Health Corp.
P.O. Box 966
Nome, AK 99762
443-5411

Southeast Alaska Regional Health Corp.
P.O. Box 2800
Juneau, AK 99803
789-2131

Tanana Chiefs Conference
201 1st Avenue
Doyon Building
Fairbanks, AK 99701
452-8255

The North Pacific Rim
903 W. Northern Lights Boulevard
Suite 203
Anchorage, AK 99503
276-2121

Yukon-Kuskokwim Health Corp.
P.O. Box 528
Bethel, AK 99559
543-3321

NOTE: In addition to the previous listings, families and others are urged to contact volunteer helping groups in their communities. Check your local directory for the numbers of groups such as the **Association for Retarded Citizens,** the **Easter Seal, Epilepsy** and **Multiple Sclerosis Societies, Parents for Autistic Children,** and the **Council for Exceptional Children.**

SELECTED READING MATERIALS

All of the following materials are available on a free loan basis from the Governor's Council for the Handicapped and Gifted, 600 University Ave., University Plaza West/Suite C, Fairbanks, AK 99701, 479-6507.

Books and Pamphlets

Providing Respite Care
A training program for respite care providers and home health aides
1982, United Community Planning Corporation
87 Kilby St.
Boston, MA 02109

Giving Families a Break:
Strategies for Respite Care
The why's and how's of operating a respite program, including models of care, recruiting and training, working with families, management and record-keeping, insurance and liability considerations
1983, Meyer Children's Rehabilitation Institute
University of Nebraska Medical Center
444 S. 44th St.
Omaha, NP 68131

Respite Care Fact Packet
Information packet in which to record special procedures for the care of a developmentally disabled person
1983, Meyer Children's Rehabilitation Institute
University of Nebraska Medical Center
44 S. 44th St.
Omaha, NB 68131

A Better Answer
by Esther Gilbertson
Two volumes:
1. Handbook for Homemaker-Home Health Aides Working with Persons with Developmental Disabilities and Their Families
2. A Manual for Instructors
1981, National Home Caring Council
67 Irving Pl.
New York, NY 10003

Foster Parents' Handbook
State of Alaska
Department of Health and Social Services
Pouch H-05
Juneau, AK 99811

Respite Foster Care Program
Guidelines and procedures from the Kansas Children's Service League
Topeka District Office
P.O. Box 5314
Topeka, KS 66605

Respite Care in Maryland
Respite care task force report from a state with comprehensive respite care services
1980, State of Maryland
Department of Human Resources
1100 N. Eutaw St.
Baltimore, MD 21201

Independent Living with Attendant Care
A Guide for the Person with a Disability
A Message to Parents of Handicapped Youth
A Guide for the Personal Care Attendant
These booklets give practical ideas and help on personal aide and attendant care
Institute for Rehabilitation & Research, 1333 Moursund Ave.
Houston, TX 77030

The following two books have been published by the Governor's Council for the Handicapped and Gifted and are available free-of-charge from that office:

What, When, Why, Where, Who, How?
A resource book of selected films, videotapes, books, speakers (and more) to increase awareness about people with disabilities

Where to Turn
A listing of services available statewide for persons with disabilities and their families

Articles

The Governor's Council also has a number of articles which relate to home and family support. Below is a selected listing:

"Improving Home and Family Support in the Doyon Region - The Graphic Record of the December 1982 Search Conference"
Proceedings of the search conference sponsored by the Governor's Council for the Handicapped and Gifted to improve home and family supports
1983, Sibbet & Associates and Responsive Systems Associates

"Helping Communities to Help Themselves: The Newfoundland Strategy,"
by Andy Baxter
An approach for promoting self-sufficiency and control for families with handicapped members

"Parents Study Group"
by Georgina Helleiner
Experiences of a group of parents in the Toronto area who lobbied for group homes for handicapped persons as an alternative to a planned institution

"The Re-discovery of the Family"
by Gunnar Dybwad
A focus on parent activism

"Survival of the Family"
by John L. McKnight
A look at the importance of human service policies that support rather than diminish family life

This book was prepared for the Governor's Council for the Handicapped and Gifted pursuant to a contract between Alaska Crippled Children and Adults and Susan DeKrey, DeKrey Communications. The opinions expressed do not necessarily reflect the official position of the Governor's Council for the Handicapped and Gifted, Alaska Crippled Children and Adults, or Susan DeKrey, DeKrey Communications.

RESPITE - A PAUSE, A BREAK, AN INTERVAL OF REST OR RELIEF

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